

New Models for Learning Disability Day Support Collaborative Phase 2

Scoping Review Summary

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Summary

Background

Phase two of the New Models for Learning Disability Day Support Collaborative includes a continued focus on the themes of inequality, the involvement of people with lived experience and supporting people to live their best lives. Programme teams are supported to utilise service design methods in their local engagement activities and a quality improvement approach to the testing and measurement of service delivery. The Evidence and Improvement for Evaluation Team (EEvIT) of Healthcare Improvement Scotland were asked to identify and summarise literature to inform the work of the collaborative, with a particular focus on:

- areas of progress and relevant considerations for data collection
- developing staff for empowerment and autonomy, and
- examples of emerging practice, including transferable learning from other sectors, such as dementia.

What we did

We carried out a structured search of key sources of grey literature to identify current research and examples of practice. We also searched the CINAHL (via EBSCO) and ASSIA (via Proquest) databases for resources on staff development.

What we found

Most people with learning disabilities now live in the community, many in mainstream accommodation, meaning that they live independently or with family, friends or housemates. There is now more research into the lives and experiences of people with learning disabilities, although gaps in data persist. Evidence suggests that aspirations have been raised, particularly among younger people.

A number of inequalities persist in health, employment and other areas of social inclusion. Self-directed support (SDS) was seen as positive in principle, but complex to navigate in practice. There are a range of views on what people would like to see from services.

Enabling positive risk taking is a key focus for staff development. A range of creative development methods were identified in the literature, including storytelling, scenario-based experience labs and ethnographic activities, to develop more flexible and open mindsets. Empowering frontline staff to work with those who use services to develop services and to solve problems on a local basis was cited as key to success in a number of contexts; doing so

requires developing managers to enable staff through coaching and mentoring and can also involve more systemic changes to budget allocation or commissioning processes. Leadership which supports staff and provides safety for decision making which is risk-enabled is crucial.

Examples of engagement demonstrate effective ways of adapting activities for meaningful engagement of people with learning disabilities and provide practical guidance for others based on experiences of strategic engagement, service and staff development.

Employment is one potential aspiration for people with learning disabilities. Targeted employability support has been found to be effective. Examples identified in the literature include supported employment models, often delivered by social enterprises and programmes which provide holistic employability support with the objective of transitioning to competitive employment, such as Project SEARCH.

There are a number of examples of services delivered through different models which offer opportunities for meaningful activity. Key learning from these services includes:

- the importance of designing services with the people who will use them and their families and carers
- the value of services which are based around the interests, skills and assets of those who use them, and offer opportunities for people to develop those interests
- the value of thinking about integrating audiences beyond target groups, including wider integration of activities within the community
- the need to develop capacity within the community to do so, which may involve attitudes, awareness, knowledge and also skills for areas such as design
- the value of wider system design (for example, age—friendly city or dementia-friendly design standards) as enabling factors for specific service design.

Conclusions

The examples identified in the literature reflect a range of possible activities which can be delivered in a variety of settings through different models.

Service transformation is enabled by development in multiple parts of the system:

- For people using services, support to develop capability to identify and navigate service options, design and commission their services and to exercise choice within the rubric of self-directed support
- For staff, to change roles and mindset, be enabled to problem-solve, be creative and flexible, to take positive risks
- For managers, to mentor and enable staff, to support problem-solving and positive risk taking, to delegate 'permission to innovate'

- For communities, to develop awareness and capabilities for inclusion and accessibility to make services and employment real options for people with learning disabilities
- For designers, planners and commissioners, to plan and implement the enabling infrastructures.

Examples relating to dementia begin to illustrate some of the systemic approaches, integrating design, community, staff and personal development.

The literature also highlighted the need to invest in community services and for people using services to inform/shape that investment to their interests/needs. There are existing models for engagement with people with learning disabilities and transferable learning, for example, the Scottish Older People's Assembly.

The specific examples of citizen's juries developed with people with learning disabilities offer helpful recommendations for developing and adapting processes for meaningful engagement.

The review also highlights the diversity of people seeking to benefit from day support, who require different levels of support and express different preferences for services. Carers are also likely to have distinct needs and internal differentiation. This is not always reflected in current data, particularly not large, national data sets, although some more targeted research captures some of the differentiation.

Introduction

Background

The People-Led Care team are working with four Health and Social Care Partnerships¹ in the second phase of the New Models for Learning Disability Day Support Collaborative.²

Phase two runs from June 2021 to March 2022 and focusses on supporting participating teams to progress through a design approach using the [Scottish Approach to Service Design](#).

Phase two includes a continued focus on the themes of inequality, the involvement of people with lived experience and supporting people to live their best lives. Programme teams are supported to utilise service design methods in their local engagement activities and a quality improvement approach to the testing and measurement of service delivery.

Scoping review

In order to inform the work of the collaborative in Phase Two, the Evidence and Improvement for Evaluation Team (EEvIT) of Healthcare Improvement Scotland were asked to identify and summarise literature relating to:

1. Culture changes following the change from hospital to community-based services, with a particular focus on any indicators of advances in equality for people with learning disabilities.
2. Summary of any reports, research or grey literature around staff empowerment / autonomy – including transferable examples from dementia sector, person-centred care, carer sector.
3. Examples of emerging practice from the learning disability sector relevant to co-design/production, employability, working differently.

In addition to identification of relevant examples and data, there was also a request to note gaps in evidence.

Methods

A structured search for relevant grey literature (for example, websites, unpublished reports and articles, survey and evaluation results) using a standard checklist protocol based upon organisations working in areas of health and care integration and service redesign was carried out. It was supplemented by a targeted search of websites of organisations and research

¹ The four project teams are from Falkirk HSCP, North Ayrshire HSCP, Perth & Kinross HSCP and West Lothian HSCP. Project teams are multi-disciplinary and are drawn from statutory and other local services.

² Information about the Collaborative, including outputs from Phase 1, can be found on the ihub [website](#).

institutions with active research programmes relevant to learning disability inclusion in the UK. The search strategy also targeted key potential sources of transferable learning, particularly focusing on other services offering day support, such as care for older people, care for people living with dementia and support for carers. The CINAHL and ASSIA databases were searched for literature on staff development for health and social care staff. Materials provided by subject experts were included in the summary and were used to inform the search strategy.

Limitations

As the approach taken was based on a rapid response, quality assessment of the literature was not undertaken.

Findings

1: Culture changes and indicators of equality

Overview

The Fraser of Allander Institute at the University of Strathclyde is carrying out a long-term programme of research and knowledge exchange focusing on the support systems available for adults with learning disabilities in Scotland. Topics include employment and the labour market, support from and for unpaid carers, social care, third sector, benefits and improving transitions. Further detail about the programme, including publications, presentations and other outputs are available on their website (<https://fraserofallander.org/research/adults-with-learning-disabilities-in-scotland/>). This programme provides a good overview of current practice.

The shift to community services

What has improved over the past 20 years?

- Most people with learning disabilities now live in the community, the majority in mainstream accommodation, meaning that people live in the community, either independently or with parents, friends or housemates (62%). An additional 14% live in supported accommodation.¹
- Statistics are now collected and reported on an annual basis, provided by local authorities.^{1,2} There is an improvement programme with Public Health Scotland to further develop the statistical data.^{2,3}

- There is now more research into the lives of people with learning disabilities and their experiences; the Scottish Learning Disabilities Observatory has led on a significant programme of health-related work.^{1,4}
- The aims of person-centred care and self-directed support are seen as positive developments, although there is a need for further resource and support to realise the aspirations fully.^{1,5}
- Research suggests that aspirations have been raised, particularly among young people.¹

Where has progress been slow?

- Estimates of the rates of employment have not improved, and are consistently lower than the average for disabled people overall^{1,6}
- Access to health services¹ and reduction of health inequalities^{1,7}
- Access to quality housing¹
- Support for parents and carers¹
- Realisation of ambitions in areas such as parenting and long-term relationships in Keys to Life¹
- Sustained budget pressure among local authorities, and the benefits of health and social care integration yet to be realised.¹

Enablers of progress were identified which supported the transition from institutional services to the community:

- Additional funding: to develop community services alongside hospitals which readied the community services for transition
- Government leadership and clarity of vision, supporting social consensus that this was the right thing to do.¹

Barriers which have limited progress toward full realisation include:

- lack of 'readiness' in society limited progress in employment, community integration and everyday activities.¹

Employment

There is no definitive dataset on the employment of people with learning disabilities in Scotland.⁶ Estimating the percentage of people with learning disabilities who are in paid employment is difficult for a number of reasons:

- Data on employment of disabled people typically provides aggregated (pan-disability) data
- Not all disabled people identify themselves as disabled to their employer
- Lack of definitive definitions and diagnostic criteria for learning disability
- Data on employment of people with learning disabilities specifically is taken from local authority data, meaning they account for only those known to local authority services.⁶

There is a significant disability employment gap in Scotland, and although existing data may under-estimate the employment rate for people with learning disabilities, it likely indicates that the rate is considerably lower than the employment rate for all disabled people.

For the period Oct-Dec 2020, the employment rate for the non-disabled population was approximately twice that of the disabled population:

Non-disabled population: 81.6%

Disabled population: 44.3%.⁶

The most recent data from the Scottish Commission for People with Learning Disabilities (SCLD)³ on adults with a learning disability known to local authorities (N= 23,584) identified 4.1% who were known to be in employment. However, 51.% of that sample have employment status as 'not recorded'. If these are removed, the employment rate is 8.4%, which is still substantially lower than the figure for the pan-disability population.^{2,6}

Data also shows that overall, disabled people in employment are more likely to earn lower wages and to work part-time.⁸

People with learning disabilities have experienced persistent disadvantage in the labour market, with higher rates of economic inactivity and lower pay over the period under study.^{6,8} Employer attitudes have been cited as an employment barrier for disabled people generally.⁸

Accessing support

There is evidence that reduction in public spending has resulted in reduction of support options and choice, although the impact varies by locality and by the level of support required.¹ In particular, people with a mild to moderate learning disability feel that there is less support as a result of the reduction of non-statutory services and tightening eligibility criteria:

- The impact varied by local authority (more affluent authorities less impacted)
- People with mild/moderate learning disabilities have been less able to access support
- Employability and community inclusion services were particularly impacted

³ The SCLD was previously known as the Scottish Commission for People with Learning Disabilities and may be referred to by that name in some documents.

- Impacts on other (mainstream) services – ie, libraries, community clubs – also impact indirectly as they are used by people with learning disabilities for a variety of activities.¹

SDS was perceived to be positive in theory, with good potential for people living with learning disabilities, which had not yet been fully realised. Two broad categories of barriers were proposed:

1. Too few services available for people with learning disabilities, which constrains choice
2. People have not been given sufficient support to make informed choices about support and care.^{1,5,9}

There was some concern expressed that the move away from building-based services may narrow options for those who prefer building-based services.¹

The Expert Group of people with learning disabilities supporting the Fraser of Allander Institute research also noted that people often did not know what their rights were.¹ Positive experience of SDS was more likely to be reported by younger users, particularly by those with parents or family members who were empowered to support them to navigate the system.^{1,10,11} This is significantly associated with socio-economic status and reflects international findings.^{1,10–12}

Day support

Researchers have begun to explore the question of how day support may develop during the Covid-19 recovery with people who access day support services.^{1,13} Issues raised in these discussions have included:

- The ‘cliff edge’ between specialist and mainstream services – can more be done to develop the capability of mainstream services to support people appropriately?
- Some users value the structure of traditional, building-based day services – it is important to understand the contribution of these services and how the benefits would be retained in any new approaches to service configuration and delivery.
- Other benefits of building-based services cited were social interaction for participants and respite for families.
- There is a view that the long-term health prospects are deteriorating because of the pandemic, which not only requires a response now but may also increase future demand, with implications for services required.
- People with learning disabilities are diverse and may have a range of different views about what they would want the services to be. Not everyone wants to go back to the services as they were. Different levels of support would also be required to access and navigate service options.

- Unpaid carers may also have different views (either from the people they care for or amongst the population of unpaid carers), particularly given the impacts the pandemic have had on them, with evidence of increasing care demands and stress.
- The type and impact of learning disability for individuals may impact on their motivation to use and enjoyment of digitally-delivered services. People with multiple and profound disabilities reported lower interest in digital services.¹³
- The innovative delivery during Covid of the third sector and community organisations was noted.
- Rural areas may have fewer community-based opportunities and may require additional investment or support for service transformation.

Data and measurement

The analysis in this section highlighted a number of issues with data which are used to measure outcomes and improvement in the lives of people with learning disabilities.

- National datasets are often not disaggregated. Even when statistics are provided on experiences or outcomes for disabled people, they are frequently not disaggregated further, so that data on the experiences or outcomes for people with learning disabilities are aggregated into a pan-disability category.
- Public authorities and most non-specialist service or employment providers will usually follow the Census definitions for protected characteristics.⁴ This results in all data on people with learning disabilities aggregated into a single category, despite the considerable diversity of learning disabilities, and frequently aggregated to the higher level of disabled persons for analysis and reporting.
- Specialist learning disability data is normally gathered and used within specialist services, but may have limited links outwith those services.
- Historically, data on people with learning disabilities has been heavily reliant on data collected through local authority services, missing out on those who do not engage with services.¹ Changes to the social care data specification are designed to widen the scope of this data to address this issue.³
- Existing research on topics like experience of SDS or risks of gender-based violence highlight the value of being able to link data on learning disability with other equalities data. ‘Intersectional’ inequalities are inequalities arising from multiple characteristics which are particular to that interrelationship, and more than the sum of their parts. They may require targeted intervention for improvement, and specific measures.¹⁴
- There are transferable examples to consider from fields such as mental health.

⁴ The protected characteristics, which are defined by the Equality Act 2010, include disability. Census definitions for the protected characteristics for 2022 are included in the full question set on the Scottish Census [website](#). Disability questions are composites of questions 18-19.

2: Staff empowerment and autonomy

Transforming services requires leadership and staff development which results in a culture of staff empowerment and autonomy.^{5,15–17} Key issues identified in the literature for staff include attitude to risk and risk enablement,^{16,18} skills and knowledge to work within human rights based approaches,¹⁸ and organisational cultures that enable 'permission to innovate'.^{15,17} Within the context of self-directed support and empowerment, the Institute for Research and Innovation in Social Services (IRISS) describes the potential of an 'emotional approach' to risk within the context of culture change to support enablement.¹⁸

The literature describes approaches for staff development which focus on developing capability for working in an outcomes-focused way, being person-centred and enabling and changing mindsets. Specific staff development approaches to enable these changes have included:

- Storytelling-based development focused on transforming management roles from command to mentoring and supporting (Glasgow Housing Authority)¹⁷
- Scenario-based experience labs which involved staff, people using services and carers as participants (South Lanarkshire day support services)^{19,20}
- Anthropological and ethnographic approaches to change mindsets and give people the tools to see situations differently (Wigan Council).¹⁵

Other methods identified in the literature include drama-based methods in which participants make choices which affect outcomes and reflect on the impact of these choices (the 'Sliding Doors' model)²¹ and facilitated human rights scenario-based discussions to enable balancing protection and risk in care (Care about Rights).²² Evaluation of interprofessional education in dementia care highlights the mediating element of the conceptual approach to risk in the profession, with greater impact of development to facilitate person-centred care in professions marked by attitudes of risk acceptance.²³

The examples in the literature also note that:

- Leadership from the highest levels is required to enable staff to make changes to ways of working and to services
- Managers need specific development to transform their roles^{15–17}
- The motivational elements of qualitative data and storytelling support changing mindsets
- Clear, shared values are important
- It may be necessary to change budgeting or commissioning arrangements so that staff are able to respond to client needs on a local level^{15,17}
- Making changes may involve changing and redefining roles and workforce composition.¹⁵

One key learning point from the Churchill Fellows programme, which focused on transfer of international best practice of creative ageing⁵ approaches to the UK context, was the need to reconsider the task-based definition and performance management of many care roles, which could be a barrier to staff engaging in the design and delivery of more creative, non-functional activities.²⁴ They found that many care roles are designed to complete functional tasks, leading staff to focus and limit their activities and to consider creative activity to be the remit of specialists, which limited opportunities for building creativity into day-to-day care.²⁴

Examples of staff development

Glasgow Housing Association: Think Yes

The 'Think Yes' model from the housing sector focused on enablement of frontline staff to make decisions about provision. This leadership-led programme took the approach of asking and enabling local staff to 'take charge of their local service and do the right thing for the customer', giving scope for working with their customers to resolve problems locally and enabling learning from mistakes. This transformation from a command and control leadership model resulted in a more responsive service, more appropriate for a complex environment. It was enabled by:

- Changing the managerial role from direction to supporting, mentoring, and responding to issues raised by frontline staff
- Providing local budgets for resolving issues for customers
- Experimentation and learning
- Clearer lines of local accountability
- Using storytelling to build confidence and spread the approach

Further details at: <http://whatworksscotland.blogspot.com/2015/07/think-yes-how-to-deliver-24.html>

⁵ Creative ageing refers to a range of arts engagement and creative activities undertaken by older people.

South Lanarkshire day centre transformation using experience lab

South Lanarkshire used the experience lab to prepare for moving from a day care centre service delivery model (where daily activities are provided), to a model that supports and facilitates individuals with learning difficulties to access lifestyle choices that they want and need in the community. The transition was facilitated by an experience lab for day centre staff to support them to learn to work in an outcomes-focused way. The case study (written in 2014) reports on the evaluation of the experience lab, lessons learned and recommendations for using this approach for development and planning.

Staff from the Institute for Research and IRISS facilitated experience lab with groups which involved day care centre staff, people who access support, carers and a member of IRISS staff. Experience lab members were given a scenario and a role to play, using their knowledge and experience. On the second round through the scenario, the work was directed using an outcome-focus visual tool, controlled by people who access support.

IRISS's case study highlights the key learning and impact of the lab methodology, and the benefits for participants. Some of the points highlighted were:

- The value of using scenarios and roles to reduce the risk that people may feel that their support arrangements might change because of their participation
- The value of peer support and reflection which resulted when mixing staff who were enthusiastic about the change with those who were more apprehensive
- Involving staff from day services across the local authority to share learning
- Ideally involving carers alongside the people they care for and social workers in the conversations

Further information is available from:

<https://www.iriss.org.uk/resources/reports/how-run-experience-lab>

<https://www.iriss.org.uk/resources/reports/working-outcomes-practitioner-experience>

Covid-19: Overcoming 'Decision Inertia'

'Decision inertia' describes situations of deferring decisions or being unable to make a decision. The Kings Fund has worked with emergency services to describe approaches for using 'decision controls' as a tactic to overcome decision inertia in complex situations (ie Covid-19). By clarifying goals, what you expect to happen, weighing up how the benefits outweigh the risks, situational awareness can be improved, and uncertainty reduced while focusing on the operational goal.²⁵

The Wigan Deal

Faced with significant financial pressures, Wigan Council undertook a systemic transformation of its services, improving health and care outcomes for its citizens despite reductions in funding and staffing. An independent review suggests that the set of core principles, described locally as ‘the Wigan Deal’ has contributed to Wigan’s success at implementing transformational change at scale and improving outcomes, while also noting some complications with attribution and measurement of positive change.¹⁵

The key components of the Wigan Deal are described as:

- working with local people in an ‘asset-based’ way that seeks to recognise and nurture the strengths of individuals, families and communities and to build independence and self-reliance
- creating a culture in which innovation is encouraged and frontline staff are permitted to make decisions for themselves and rethink how they work
- empowering communities, including by investing in local voluntary sector organisations and community groups
- creating the conditions for closer partnership working between agencies.¹⁵

Changing the relationship between staff and the people they support was essential to making this transformation. This required:

- Developing staff knowledge, skills and confidence to carry out holistic conversations with the people they support, exploring their context and what they wanted to achieve before moving onto assessment (described as ‘a more anthropological approach’ and ‘leaving behind preconceived ideas’)
- Staff training included theory and practical ethnographic techniques
- Training non-public facing staff in ethnographic approaches as well for whole-system understanding and buy-in
- Enabling positive risk taking by staff and clients, supported by management, as they work in partnership to achieve outcomes
- Developing a contracting or charter approach with citizens (give-get) based on models of shared responsibilities to clarify roles and manage expectations

Establishing 'permission to innovate' is supported by:

- Enabling positive risk taking, providing staff with a 'we will back you' message
- No-blame culture, where staff are supported if things do not work
- Sharing individual case studies to illustrate and encourage innovation and flexibility
- Constant reinforcement of messages by managers
- A focus on listening in leadership – listening to local people and to staff

Results of staff surveys and other measurements indicate positive staff engagement and experience resulting from these changes.

Changes in Wigan have involved significant transformation of the social care workforce, including development of new roles and changes in workforce composition. The Council transformed their day support offering, reducing their number of day centres from 14 to 4 and commissioned voluntary and community organisations to create new and more diverse services to replace them. Some services are delivered through community hubs, with staff who have undertaken the Deal training.

Change has been enabled in Wigan by:

- Shared values and principles
- Investment in voluntary and community services
- Sharing user stories to encourage and drive change
- Staff training and development
- Enabling and empowering staff to work differently with people
- Citizen-led community health approaches, including Dementia Friends and Community Link Workers
- Multi-agency collaboration enabled through place-based working

Further information is available from: <https://www.kingsfund.org.uk/publications/wigan-deal>
<https://www.kingsfund.org.uk/blog/2019/07/wigan-positive-approach-risk>

Lessons from the Churchill Creative Ageing programme

The Winston Churchill Foundation collaborated with The Baring Foundation to fund 47 Churchill Fellowships in a 'Creative Ageing' programme. The Fellows, drawn from a variety of arts and care backgrounds, researched international practice and developed approaches to implementing person-centred, creative aging practice within the UK. They identified a number of recommendations relevant to staff development²⁴. Specific issues for staff training include the challenge of task-focused approaches to defining staff roles, so that 'creativity' would be outwith the remit of many care support staff. Issues of transactional approaches to care provision and different specialisms are discussed, including the need for better integration with creative professionals²⁴. Creative professionals would also benefit from support, including better connections with health and care professionals and with each other²⁴. The examples of practice are delivered in a variety of settings, including arts organisations.

Further information is available from: <https://cdn.baringfoundation.org.uk/wp-content/uploads/2017/06/GrowingTheCreativeAgeingMovement-Final-PDF.pdf>

3: Examples of emerging practice and transferable learning

This section describes examples of practice from the literature on learning disabilities, supporting older people, living with dementia and supporting carers. It highlights key learning from examples in three major areas which have been highlighted as topics of interest:

- Coproduction and co-design: involving people in the design and development of programmes and services and setting priorities
- Employment
- Different ways of designing and delivering services.

Coproduction and co-design

Research Voices Citizens' Jury

The Scottish Learning Disabilities Observatory and Talking Mats, funded by the Wellcome Trust, began the project in 2018. They established a citizen's jury comprised of people with learning disabilities with the aim of deliberating:

How can people with learning disabilities influence health research? Including influencing:

- What research is done to help people with learning disabilities
- How this research is done

The standard citizen's jury model was adapted to make the process more accessible. There was a focus on developing skills, confidence, knowledge and trust within the group to empower participation – developed through five preparatory workshops.

The adapted model

Key features of the adapted model included:

- Accessible communication, including use of the accessible communications framework resource Talking Mats²⁶, easy read material and graphic facilitation enabled participation
- The group set their own question and agenda
- The jury took place over five sessions over two weeks – extended time for deliberation was important for empowering participation. A range of tools to support engagement and debate were used.

Learning from the Citizen's Jury

Ethnographers observed that for adapted juries, 'the performance of engagement does not always indicate engagement' (p. 14); that is, people may express their engagement differently and in unexpected ways. This led to the recommendation to 'normalise and accept different styles of listening and learning.'

Evaluation highlighted the importance of the social impact of participation for participants as well as the 'outcome' of the jury, which may be useful to consider in outcome measures. The need to respond to what motivates participants was noted as a key learning point.

Talking Mats were used in the evaluation to measure increases in knowledge and confidence and were an effective way of doing this.

Facilitation tips

Facilitation was important in ensuring success, particularly because many participants had little previous experience of group work. Participants usually related to the process through the lens of personal experience, which meant that they may be sharing stories which can result in emotional vulnerability. The personal stories were also recognised as adding depth to the deliberation. A key recommendation is to consider having support in place to respond to this.

Challenges with memory could be a barrier to deliberation. Graphic facilitation was the best means of overcoming this; recaps were also useful.

Expert witnesses mainly reported positively about their experiences. Presenters may need support from the facilitation team to adapt their presentations and material and time should be planned for this.

Planning for the conclusion of engagement exercises is also important, particularly in light of their social benefits for participants. Ending is a social transition for participants and planning is required to manage the impact of no longer seeing peers and staff.

For further information and resources, see:

<https://www.sldo.ac.uk/media/1939/rv-evaluation.pdf>

Living well in later life in Scotland: Involving Older People in Transforming Care

This project reports on the process and impact as of April 2015 of the cross-sector improvement network which supported health, housing and care partnerships to use the £300 million Change Fund attached to Reshaping Care for Older People, with a focus on delivering preventative care, enhancing independence and wellbeing²⁷. Involvement is reflected in the principles for the Change Fund plan.

Representatives from the Scottish Older People's Assembly (<http://www.scotopa.org.uk/>) coproduced the principles for delivery, based on themes that older people had identified as being important to them²⁷.

The five underpinning delivery principles they agreed were:

1. meaningful involvement of older people – take into account the diversity of the older population, and promote principles of fairness, respect, equality and dignity
2. focus on outcomes that matter to older people – prioritise actions that older people seek and value, informed by views from members of the SOPA
3. be ambitious but focus on the practical and achievable – prioritise actions that are innovative and do good, do no harm and are achievable within three years
4. address specific needs of inequalities groups, and
5. build on evidence and experience from the national and international events on active and healthy ageing held in Scotland during 2012, and plausible theory where evidence is limited.

The case reflects an example of strategic steering by a representative assembly and of working through the representative assembly to establish working principles and to set priorities for transformational change.

Guiding principles for the Transformation Plan, co-designed with older people:

1. involve older people in design of support for wellbeing
2. raise awareness of the benefits of physical activity
3. give GP practices a central role to signpost people to local support
4. recognise the vital role that volunteers can play
5. consider design, lighting, location, access and transport issues
6. create active communities for all life stages
7. join up effort across sectors and policy areas
8. provide information, choice and more opportunity to self-manage
9. create opportunities for having fun and being sociable
10. challenge ageism
11. create opportunities for learning, volunteering and employment in later life, and
12. promote intergenerational activity.²⁷

In developing and delivering Reshaping Care, older people identified four themes that were important to them:

1. “I want to have fun and enjoy myself”
2. “I wish to remain connected to my friends”
3. “I wish to be able to contribute to society for as long as I want”, and
4. “Don’t talk about me without me, and respect my beliefs and values”.²⁷

The themes of this programme highlight the importance of:

- Social connection
- Having a range of activities and opportunities within the community
- The value of involving users of services in strategic transformation
- The need to challenge stereotypical thinking
- The role of information and support in enabling choice and self-management
- The potential of integrated (in this case, intergenerational) activity. Many of these themes also appear in work on age-friendly cities and dementia-friendly communities, which are discussed further, below.

Examples of outcomes are discussed and further details are provided in the Reshaping Care and Change Fund Building on Progress Fund, Joint Improvement Team, 2015, <http://www.jitscotland.org.uk/resource/reshaping-care-for-older-people-change-fund-building-on-progress-june-2015/>

Employment

Although employment may not be an appropriate outcome or destination for all people with a learning disability, there is evidence that some people with learning disabilities aspire to paid employment and value the economic independence this affords.⁶ Specialist employability support, particularly supported employment models, have been shown to be effective for disabled people, and people with learning disabilities benefit most from specialist support and employability programmes which have been designed to meet their needs.⁶ There is some debate in the literature about the relative benefits of supported employment as compared to specialist employability support which aims to develop individuals with skills, knowledge and experience for employment in the ‘open’ labour market.

A systematic review of interventions for improving employment outcomes for persons on the autistic spectrum found that vocation-focused employability programmes which developed work-related skills, including Project SEARCH, had positive impacts on employment outcomes

compared to controls.²⁸ Project SEARCH in particular had improved outcomes at both nine and 12 month intervals post-intervention.²⁸

Researchers also identify a need to overcome low expectations of people with a learning disability and to support them to develop their confidence to move towards work.²⁹

Models of targeted employment support

Supported employment

Supported employment services are available in most of Scotland's local authority areas. Guided by the five stage approach set out in the Supported Employment Framework, they offer targeted and holistic employability services which have been found to be a preferred model for people with learning disabilities.²⁹ Supported employment is structured around long-term support for employers and individuals.²⁹

Examples of supported employment

All in Edinburgh – a partnership for supported employment

All in Edinburgh³⁰ is a supported employment service which is run by The Action Group, ENABLE Works, Forth Sector and IntoWork. They provide holistic services matching clients with businesses for supported employment. During the period 2015-2019, All In Edinburgh supported 492 clients with a learning disability, making people with learning disabilities one of their most significant client groups.

Interviews with employers in an evaluation of the programme found that about half had no previous experience of supported employment. For these businesses, engagement and support from AIE helped to overcome any concerns they may have had about providing supported employment³¹. Employers' motivations for engaging with supported employment varied; many were motivated by interest in supporting the target groups or by corporate social responsibility objectives³¹.

AIE delivers an employability service with fidelity to the five stage Supported Employment Framework. They have supplemented this with a welfare rights service which resulted in £1.9 million direct financial gains for project beneficiaries during 2015-19³¹.

Further information is available at: <http://allinedinburgh.org.uk/>

La Fageda – A social enterprise providing supported employment

La Fageda is a social enterprise with a focus on employing disabled people (among other pro-social goals, including environmental sustainability), with a specific focus on supporting employment for people with learning disabilities or mental health conditions. Founded in the 1980s by psychologists, the enterprise developed a strong brand and profitable business centred around organic and sustainable yogurt and jams, produced with local raw materials and sold within Catalonia. In 2010 they expanded to open a new production facility in an urban area to make ice-cream. The core aim was 'to create a profitable company that would integrate all people with intellectual disabilities or chronic mental illness in their region.' Approximately 70% of their staff of 300 are disabled.

Income is reinvested in provision of occupational therapy services for the wider community. Management, therapists and care workers are on staff, able to support and tailor work to individuals (and to provide additional support where required).

La Fageda has also required novel organisational responses; being constituted as two foundations and a cooperative society in response to Spanish legal structures.

Further details are available from:

<https://www.elcuartosector.net/en/post-historia/lorem-ipsum-dolor-est/>
<https://www.theguardian.com/society/2016/jul/03/cultivating-a-workers-paradise-la-fageda-mental-illness-spain>

Harvard Business Review Case Study (requires subscription or purchase):

<https://store.hbr.org/product/la-fageda/711452?sku=711452-PDF-ENG>

Support to transition to open employment

Project SEARCH

Project SEARCH is transition-to-work programme which focuses on supporting young people with learning disabilities to make the transition into competitive employment³². Advocates of this approach argue that competitive employment offers a greater range of career opportunities and increased likelihood of career progression, although considerable investment in developing employer capability is required⁶.

Project SEARCH is a business-led, workplace-based development programme which includes employability skills development and a series of three targeted internships which enables the participant to develop marketable skills.

Local programmes are delivered to an international standard defined via the Core Model Fidelity.³³ A number of Scottish local authorities and health boards in NHSScotland deliver the programme; support is provided through recruitment, placement and job coaching.³⁴

Further information about the Project SEARCH model is available at <https://www.projectsearch.us/transition-to-work/>

Project SEARCH in NHSScotland information is available from <https://www.careers.nhs.scot/projectsearch>

There is increased focus on the use of apprenticeships as opportunities to provide disabled people with routes into career opportunities in Scotland. Skills Development Scotland administered a programmed of enhanced support apprenticeships, delivered by Open Doors Scotland, and has established targets for increasing the percentages of disabled people undertaking apprenticeships. Available assistance includes specialist employer services (such as mentoring, training for colleagues, site orientation visits, job coaching) and support for funding applications via Access to Work.³⁵ Skills Development Scotland has successfully increased the uptake of apprenticeships by disabled people, although their data are not further disaggregated, so there is no specific information on opportunities for people with learning disabilities.³⁵

Entrepreneurship and micro-enterprise

There are fewer models in the literature for supporting self-employment and entrepreneurship. The evaluation of All in Edinburgh found that a lower percentage of people engaged in support employment eventually wound up in self-employment (as opposed to other models of employment), and did not provide information on what percentage of self-employed clients were people with learning disabilities.³¹

The SCLD reports on a case study of support for business development under the Keys for Life Development Fund, but notes the challenges of supporting this type of employment model with short-term funding given the extended period of time required to establish and launch a new business.³⁶

Social Care Ideas Factory: Wee Enterprizers

Wee Enterprizers was a project funded under the Keys for Life Development Fund with the aim of supporting people with learning disabilities to develop potential business ideas. Through a series of workshops and partnerships, participants were supported to develop business plans, networks, marketing ideas and to begin to set up micro-business.

The focus was on supporting potential entrepreneurs to develop business knowledge and skills to build on their existing interests and aspirations.

One challenge noted was the timescale of project funding; noting that it normally takes approximately three years for a new business to become established.

Further information about the case is provided by the SCLD, including key learning and recommendations for others interested in taking forward similar work in their report on employment projects at: <https://www.sclد.org.uk/building-bridges-policy-practice-resources-presentations/>

Working differently/different models of delivery

There are a range of approaches seeking to develop and sustain different models of delivering day support or related activities. This section describes a selection of examples from learning disability services and transferable fields, including inclusion strategies for older people, dementia services and support for carers.

Keys for Life: Social Connectedness Projects

Funded by the Scottish Government in 2015 as part of the implementation of Keys for Life, the aim of these projects was to develop and test new ideas which would make a positive difference in the lives of people with learning disabilities.

Four projects were run under the 'social connectedness' theme:

- **Fit's for Supper** (Aberdeenshire Council), an intergenerational and multi-ability supper club, where participants learn to prepare a new dish and eat it together each week
- **Cantray Crew Connects** (Cantraybridge College), a social network of existing and former students at the college which functions as an alumni association as well as delivering social and health-based activities
- **Growing for Growth** (East Dunbartonshire Council) addressed health inequalities by establishing a community garden and supper club which included cooking lessons, and
- **Befriending Project** (Interest Link Borders), which supported group and one-on-one friendships for children, young people and adults, supported by volunteers from the community.

The report describes what each project did, outcomes, the investment required, learning from the projects and recommendations for running similar projects. Some projects include information about how outcomes were evidenced.³⁷

Common themes include:

- the need for flexibility
- strong, dynamic partnerships with the organisations you will work with
- ensuring the right people are involved, with the right skills and development support (whether paid staff or volunteers).

Further information is available from: https://www.sclld.org.uk/sdm_downloads/social-connectedness-projects/

Activity redesign examples

Meaningful days

This position paper from Scottish Care summarises evaluation findings from a number of change projects across the UK in which self-directed support approaches delivered different ways of enabling people to access meaningful day support activity. Although the primary focus is on older people's experiences, there are case study examples of people with learning disabilities, and the paper argues for the transferability of the approach. Recommendations include:

- transition service delivery to an integrated community approach
- empowering individuals to select and even create services driven by their own interest, knowledge and skills
- breaking down artificial 'target group' silos for more integrated, community-based activity and engagement⁵.

The paper discusses investment and commissioning models for SDS to support these recommendations, noting that commissioning may require an approach which stimulates and develops local services to which people may be referred, and that disinvestment in some existing services may be required to release funding for further investment⁵.

Evaluation of pilot projects found that:

- supporting people to pool and use their own budgets to access and fund services which meet their needs and interests can reduce costs and stimulate the local economy
- in many budgets were tied up in contracted services or buildings, requiring strategy for disinvestment to release funding
- community development is required to ensure that there is effective choice of activity and that activities are accessible
- staff reported increased motivation and greater job satisfaction when they felt empower to be flexible and develop ways of working to meet their clients' needs.⁵

A full copy of the report is available from: <https://scottishcare.org/wp-content/uploads/2019/11/Care-Cameos-Meaningful-Days.pdf>

Shared Lives

Shared Lives is a model of 'family-based support where service users are included in the family and community life of a "Shared Lives carer", who uses their family home as a resource'³⁸. Day support is one of the services which can be provided through the scheme. Shared Lives is a small proportion of social care in Scotland.

As of April 2020, 553 people were supported in Scotland through Shared Lives by 361 carers; one third of those supported live with a learning disability³⁹.

Evidence of the impact of Shared Lives as compared to other support models is limited, but a small scale study comparing quality of life outcomes of Shared Lives service users to other care users found more favourable outcomes among older people. The authors note some limitations, including questions as to the extent to which the two samples were comparable in terms of characteristics, but they concluded that Shared Lives offered benefits in terms of control and choice of daily activities and a sense of belonging³⁸.

Further information is available from: <https://sharedlivesplus.org.uk/news-campaigns-and-jobs/growing-shared-lives/scotland/>

Yoga for Me

Flexible Options (Newport, Wales) supports adults with learning disabilities to access activities of their choice. This paper describes the development of their Yoga for Me offering, a person-centred approach to teaching yoga for people with learning disabilities.⁴⁰

The authors discuss their approach to adapting the standard yoga class structure so that it would be accessible, considering physical abilities, concentration and ways of communicating. Support workers employed by Flexible Options were allocated to participants to provide assistance and guidance. Class plans are typically adjusted on the day to respond to their participants' moods and needs. The importance of fun for teaching more demanding elements was highlighted.

Participants particularly enjoyed the mindfulness elements. The process of successfully adapting Yoga for Me for online delivery during the pandemic was discussed. The Yoga for Me approach was developed by specialist nursing practitioners who are also yoga instructors. They note that there are very few specialist instructors for adults with learning disabilities.⁴⁰

Further information is available from:
<https://journals.rcni.com/doi/10.7748/ldp.2021.e2124>

Enhanced sensory dementia care

This evaluation reports on a pilot Alzheimer Scotland programme of Enhanced Sensory Day Care, offered to service users with dementia whose day care needs could no longer be met by current standard service due to progression of their dementia.⁴¹

The model is a sensory-based, non-pharmacological intervention with a focus on making connections with a person in later stages of dementia through some or all of the five senses, tailored to individual preferences and wishes.

A range of sensory interventions were used:

- photographs and effects of light, special photograph books
- food, scents of perfume/aftershave, oils, flowers
- personal music, singing, musical instruments, noise-making toys
- doll therapy, soft toys, massage
- foods
- physical movements.

Models of sensory care have been developed in learning disability residential settings (Snoezelen in the Netherlands), which informed this initiative.

The pilot study suggested that a partnership approach, fostering communication between individuals receiving care, their families and care providers in the implementation of the sensory model would contribute positively to quality of life for people living with advanced dementia.⁴¹

Further information is available from:

https://www.alzscot.org/sites/default/files/images/0001/6601/ESDC_final_report.pdf

Farm-based day care

Farm-based day care (FBDC) options offer people living with dementia the opportunity to spend days participating in horticultural and agricultural activities in a farm setting. Examples can be found in the Netherlands and the Nordic countries.

Studies of FBDC in Norway found that:

- activities took place outdoors more often than standard day support⁴²
- being outdoors was strongly associated with improved quality of life⁴² and positive mood⁴³
- activities required higher levels of physical activity,⁴² social interactions,^{42,43} interaction with animals,⁴² familiar or everyday activities⁴³

Based on the learning from FBDC, the authors recommend that quality of care in regular day care could be increased by incorporating more familiar, everyday activities, which other studies have shown to be positively related to sense of identity.⁴³ They also argue for improved utilisation of outdoor spaces, particularly to enable physical activity.⁴³

Further information is available from:

<http://onlinelibrary.wiley.com/doi/abs/10.1111/hsc.13113>

<https://onlinelibrary.wiley.com/doi/epdf/10.1111/hsc.12937>

Principles of the farm-based care approach can be adapted into other care settings, including long-term care. For more on the application of green farm-based care approaches in long-term care settings, see:

<https://www.cambridge.org/core/journals/international-psycho geriatri cs/article/innovating-dementia-care-implementing-characteristics-of-green-care-farms-in-other-longterm-care-settings/DAB9F57689D3CEDA1211E48861DA71D6>

System/community approaches

Examples in this section seek to make wider changes within communities to foster inclusion of people who require support within the wider systems and activities of the community. This requires attention to planning, design, community development and social and cultural approaches to inclusion.

Both Age-Friendly Cities and Dementia-Friendly Communities are approaches which focus on developing individuals, organisations and systems to support older people and people living with dementia to be active, independent and engaged as possible within their communities. Achieving these aims requires accessible design, awareness raising and changing attitudes and developing activities and services within the community which are suitable (ideally co-designed with the users themselves).^{44,45}

Dementia-friendly communities

The Alzheimer's Society's dementia-friendly communities programme takes the approach of developing people and organisations to share responsibility for making their communities more dementia-friendly. They define a dementia-friendly community as one where 'people with dementia are understood, respected and supported', and offer a public recognition scheme, guidance, awareness raising and training resources.⁴⁶

Dementia Friends is an initiative focused on developing individual awareness of what it is like to live with dementia, and ways that people can help those living with dementia in the community in small ways on a day to day basis. It is often delivered as part of a Dementia-Friendly Communities initiative as an approach to engage the wider public.

Evaluation of the implementation of Dementia-Friendly Communities in England found that:

- There was no universally agreed definition of 'dementia-friendly community', and approaches to implementation varied
- Dementia-friendly community might be better understood as an ongoing process, and
- The extent and type of involvement of people living with dementia and people affected by dementia in the design and implementation of programmes varied.

A survey of the experience of people living with dementia who live in dementia-friendly communities carried out as part of the evaluation found that:

- About half were aware that they were living in a dementia-friendly community
- This awareness was associated with a number of positive community engagement measures, such as taking part in activities and feeling valued by the community.

The authors noted the value of including measures which reflected positive outcomes for people living with dementia and involving them in the evaluation and audit of the programme.⁴⁷

Further information on approaches to Dementia-Friendly Communities is available from:

<https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities>

Information about Dementia Friends is available from: <https://www.dementiafriends.org.uk/>

The final report of the evaluation of Dementia-Friendly Communities in England, with recommendations for practice, can be accessed from:

<http://uhra.herts.ac.uk/handle/2299/23477>

“Many people living with dementia still enjoy and engage in activities.... when these activities were located within mainstream services and organisations (e.g. shopping centres, eateries, leisure and sports centres), they had the potential to bridge the experience of living with dementia with everyday life, providing continuity and normalising the needs of people living with dementia... where these activities were separate and standalone...they appeared to have less impact on the wider community and were harder to sustain.”⁴⁷

World Alzheimer report 2020: design, dignity, dementia: dementia-related design and the built environment: Volume II: case studies⁴⁸

The annual World Alzheimer report presents an international survey of best practice in dementia-related design and the built environment. This volume of the World Alzheimer report 2020 presents, in case study format, the information gathered by the survey described in volume 1. The aim is to illustrate the worldwide efforts that are being made to design buildings that meet the needs and aspirations of people living with dementia and those who care for them. Information about the case studies was collected via self-report survey. The majority describe health and care settings, including day centres, but five focus on public buildings which have been designed with specific focus on dementia, and also discuss the services and activities which take place within them

There are a number of common elements in design highlighted in the case studies which support safety, wayfinding, managing levels of stimulation, familiar furnishings, social and personal spaces.⁴⁸

Dementia-Inclusive Resource Centre (Fredericton, New Brunswick, Canada)

The Alzheimer Society of New Brunswick is located in this building. They worked with the building owner on design of a dementia-inclusive space for all occupants, with the result that other services in the building developed their services to be more dementia-friendly. The dental practice located in the building has developed a facility specifically for those with sensory challenges and those living with dementia and the Alzheimer Society will be training all their staff.

Atria Shopping Gallery (Petaling Jaya, Selangor, Malaysia)

The Atria-ADFM Community Centre (AACC) provides a walk-in centre within a shopping mall where people can get information, attend talks and join a caregiver's organisation. They also organise and run a range of events and activities for people living with dementia. The centre is integrated into the shopping centre, enabling people living with dementia to be with people from the wider community and making it easy for others to get information and learn about dementia. Caregivers can also access support and respite which is integrated with shops.

Deichman Oppsal (Oslo, Norway)

Deichman Oppsal's vision is to be an age and dementia-friendly public library. The aim is to provide activities to stimulate social contact within an environment that is a cultural and social meeting place. This library is a pilot project. Library staff and local health care staff jointly participated in a one-day educational workshop; providing input following the workshop to inform development of the physical environment and services of the library.

HortPark Therapeutic Garden (Singapore)

This garden, which opened in 2016, is located within a larger public park. Developed by the parks authority in consultation with a Professor of Psychological Medicine, it aims to 'contribute to the wellbeing of all visitors, including those with conditions such as dementia.' In addition to core dementia-friendly design elements, it is staffed by trained guides, and activities reflect a range of sensory experiences, creative pursuits and engagement with nature.

Broomhill Gardens Horticultural Training Co. (Glasgow, Scotland)

The centre is a community hub designed for all the community, including those living dementia, to enjoy. In addition to a café and gardens, it also hosts activities to promote digital inclusion, knitting and fitness classes. The café and gardens offer an informal space which can be enjoyed by people with dementia, their carers and families within a wider context of integration with the community. Staff are trained to support the mental health needs of the centre's users.

All the design examples are available from: <https://www.alzint.org/resource/world-alzheimer-report-2020/>

Overall learning from the design examples:

- Focus on redesigning public space with the requirements of people living with dementia in mind.
- Aim of increasing integration into the community and reducing isolation.
- Spaces support people living with dementia and carers.
- Designed to maximise independence, orientating and supportive of individual's needs.
- Activities are also integral to the planning.
- Focus on staff training and expertise.
- Some reflect planning with others and co-location to develop capacity/share expertise.

Digital tools for empowerment

This section describes examples of digital tools developed by and for people with learning disabilities with the aim of addressing specific issues of concern to them.

PAMIS Digital Passports⁴⁹

Awarded the 2020 Self-Management Digital Innovator Award by the Health and Social Care Alliance, this digital 'passport' is a flick-through e-book which contains information about a person and which they can use to express their needs. The passport is a digital version of the paper Personal Communication Passport. PAMIS worked with family carers of people with profound and multiple learning disabilities to develop first the paper version and then then digital version.

The digital passport is being used by people to express their interests, support them to maintain social contacts, to aid care planning, train carers and to interact with others in a variety of environments.

Further information is available from: <https://pamis.org.uk/services/digital-passports/>

Human Rights Town⁵⁰

In March 2021, the National Taskforce for Human Rights Leadership recommended incorporation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) into Scots law. Scottish Government has included incorporation of UNCRPD rights as one of their commitments for this term.

This digital app, developed by Scottish Commission for People with Learning Disabilities and the Publishing Bureau, has the aim of empowering people with learning disabilities to recognise and realise their human rights.

Using gamification and interactive scenarios, users travel around a 'human rights town'. The scenarios are based on daily activities such as using public transport, going to work. Users are presented with information about the specific human rights under the UNCRPD relevant to the situation. There are interactive questions about whether they think that human rights are being met in the scenarios.

People with learning disabilities led development of the app and provided the voice-overs.

The aim is to support the realisation of human rights in practice, developing awareness of the rights in the UN Convention, supporting the commitment to make them real for people with learning disabilities in their communities and day to day life.

The app is currently available through both Google Play and Apple App stores. Further information is available from <https://www.sclld.org.uk/human-rights-town-app/>

Conclusions

The examples identified in the literature reflect a range of possible activities which can be delivered in a variety of settings through different models.

Service transformation is enabled by development in multiple parts of the system:

- For people using services, support to develop capability to identify and navigate service options, design and commission their services and to exercise choice within the rubric of self-directed support
- For staff, to change roles and mindset, be enabled to problem-solve, be creative and flexible, to take positive risks

- For managers, to mentor and enable staff, to support problem-solving and positive risk taking, to delegate 'permission to innovate'
- For communities, to develop awareness and capabilities for inclusion and accessibility to make services and employment real options for people with learning disabilities
- For designers, planners and commissioners, to plan and implement the enabling infrastructures.

Examples relating to dementia begin to illustrate some of the systemic approaches, integrating design, community, staff and personal development.

The literature also highlighted the need to invest in community services and for people using services to inform/shape that investment to their interests/needs. There are existing models for engagement with people with learning disabilities and transferable learning, for example, the Scottish Older People's Assembly. The specific examples of citizen's juries developed with people with learning offer helpful recommendations for developing and adapting processes for meaningful engagement.

The review also highlights the diversity of people seeking to benefit from day support, who require different levels of support and express different preferences for services. Unpaid carers are also likely to have distinct needs and internal differentiation. This is not always reflected in current data, particularly not large, national data sets, although some more targeted research captures some of the differentiation.

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or email his.contactpublicinvolvement@nhs.scot

Improvement Hub

Healthcare Improvement Scotland

Edinburgh Office
Gyle Square
1 South Gyle Crescent
Edinburgh
EH12 9EB

0131 623 4300

Glasgow Office
Delta House
50 West Nile Street
Glasgow
G1 2NP

0141 225 6999

www.ihub.scot