A Time to be Bold

Scotland-wide learning from the GDA Future Visions projects.

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'A Time to be Bold'

This is a time to be bold, That's what was said, A time to progress, reassess and rethink unafraid. A time to be bold and redesign our system of care, A time to shift the paradigm to create a model that's fair.

We need to rethink that social care is a burden to society: It's an investment in our citizens, helping to maintain propriety. We should stop talking of competition and transactions, and reimagine it as a model of collaboration and positive actions.

Our foundations are already strong, but now we need to start building; Increase self directed support and a fund for Independent Living. Nurture our amazing social care staff, they should feel valued and engaged. We need networks and respite for the carers that are unwaged.

We should re-legislate care – bold, brave, empathetic and vocal; Build partnerships to decrease the red tape nationally and local. We need accountability, with rights based approached embedded, And support to get our voices heard, participate and be represented.

We need a system of redress when rights have not been upheld, And recourse to complain when mistakes and injustice are felt. We must now start to measure the outcomes which actually count, Alongside those people the services are supposed to be about!

This is a time to be bold, so here are the questions we ask: How do we drag our social care system out of the past? How do we make it a springboard for choice and control, That enables disabled people to take up our rightful roles?¹

¹ The poem was inspired by disabled members of GDA's Social Care Expert Group and was written by Johnny McKnight, creative writer, director and educator for GDA's Purple Poncho Players. The poem was performed as part of a performance for Scotland's Minister for Wellbeing and Social Care.

Executive summary

This report draws on eleven years' learning from consecutive Future Visions for Social Care projects that have been funded by the Scottish Government and delivered by Glasgow Disability Alliance. GDA is a Disabled Person's Organisation with over 5,500 diverse disabled people as members, and a wide network of partners and allies who support its aims. GDA's accessible programmes remove barriers and build capacity, and its community development approach seeks to empower disabled people to be leaders in their own lives.

Future Visions for Social Care has developed into a unique programme that combines support for disabled people in the Glasgow region to find pathways to independent living, plus a Social Care Expert Group that seeks to influence social care and National Care Service policy at local and national levels. These activities support Scottish Government aims to progressively support independent living, including through Self-Directed Support, and to sustain collaboration and co-design in developing and implementing NCS and social care policy, both locally and nationally.

The report makes an analysis of the learning across several iterations of Future Visions for Social Care, including the current 2022-23 project. Eight core elements are key to the success of the work. The eight core features are:

- 1. A disabled people-led organisation with statutory investment from the Scottish Government, commissioned to work with each local IJB on a sustainable basis.
- 2. A track record of removing barriers to disabled peoples' participation, understanding disabled peoples' lived experiences, and commitment to independent living.
- 3. Local knowledge and contacts and to be able to facilitate and sustain relationships with a wide variety of statutory, third sector and community stakeholders.
- 4. A holistic ethos, to be able to support diverse disabled people to actualise their preferred social care outcomes.
- 5. Disability equality and independent living expertise must be held in order to deliver disability equality training and independent living masterclasses to social care policy makers, service developers, service providers, and politicians.
- 6. Community navigation in the form of case work along with coaching approaches where needed for individuals using or needing social care.
- 7. Enabling peer support amongst disabled people using or needing social care.
- 8. A community development approach to build collective capacity enabling disabled people to participate in policy, practice, research, and leadership as a group.

The first element (the need for Scottish Government investment) is what drives the title of this report: **A Time to be Bold**. The report argues that in order to fulfil the ambition of collaborative reform of social care and to achieve the wider aim of the National Care Service to achieve consistency and equality in social care in every area of Scotland, a disabled-people led organisation needs to be sustained in every Integration Joint Board area, to lead a Future Visions-style programme. This needs to be a Scottish Government investment. A bold, strategic investment in disabled people-led groups will both drive fulfilment of independent living outcomes and provide a collective and ongoing voice into social care policy for disabled people, both locally and nationally.

1. Introduction

The Independent Review into Adult Social Care (IRASC) (Scottish Government, 2021) proposed a National Care Service (NCS) for Scotland, to encompass social care services. A prime argument for a nationally co-ordinated service has been to achieve consistency and address inequalities (Scottish Government, 2022). IRASC also underscored that people needing and using social care should be involved in improving social care policy and practice (Scottish Government, 2021, p.21):

Throughout the report, we stress the importance of partnership and collaboration, and of amplifying the voice of staff and of people who need social care support. That is true at every level and in every part of the system... People with lived experience must be partners in the commissioning process and integral to decision-making and prioritisation, monitoring progress and making improvements; nothing about me, without me, as the saying goes.

IRASC also made three recommendations (8, 30 and 32) that emphasise the need for more *'peer services', new approaches'* to involvement, and a *'collaborative, rights-based and participative approach'* to be taken by commissioners of social care. These would enable disabled people to better understand their rights to social care and options for Self-Directed Support (SDS) to enable independent living. The recommendations of IRASC have been put into practice in the principles of the <u>National Care Service (Scotland) Bill</u> (Clause 1). These place the realisation of human rights, enabling people to thrive and fulfil their potential, enabling communities to thrive and prosper, dignity, equality, inclusion, prevention, and collaborative service design at its heart.

This report draws on eleven years' learning from consecutive social care-related projects that have been funded by the Scottish Government and delivered by Glasgow Disability Alliance. GDA is a Disabled Person's Organisation with over 5,500 diverse disabled people as members, and a wide network of partners and allies who support its aims. GDA's accessible programmes remove barriers and build capacity, and its community development approach seeks to empower disabled people to be leaders in their own lives.

Evidence from the **GDA's Future Visions** projects has been gathered since 2012 in various funded projects which initially aimed to support the rollout of Self-Directed Support and build disabled people's capacity to engage with this option of Social Care. For eleven years, Future Visions has supported an increased understanding of SDS and social care rights - including exploring independent living for disabled people needing or using social care, including SDS. This resulted in GDA's work being considered of national significance to the Scottish Government's Social Care Reform Programme. The earlier projects were part of Support In the Right Direction (SIRD) and ended 31st March 2018. From December 2018, the work was aligned to the Social Care Reform Programme, and was then amended in response to the Covid-19 pandemic from March 2020 when GDA swiftly responded to the needs of disabled members and disabled people more widely. During this time, GDA continued to sustain a focus on building knowledge, capacity and understanding of social care and related human rights amongst disabled people, and to share lived experience and insights, including contributing to IRASC amongst other consultations.

Through consecutive projects, Future Visions for Social Care has ultimately shown the potential for disabled people-led organisations in every Integration Joint Board (IJB) area in

Scotland to bring people who need or use social care together to enable two outcomes. First, enabling disabled people to have more individual choice and control over independent living. Second, supporting disabled people to collectively influence both local and national social care policy and practice, including through a <u>Social Care Expert Group</u>.

This short report summarises that Future Visions evidence. Drawing together the themes from this, the report **recommends** that to unlock the NCS twin ambitions of collaborative reform of social care and achieving consistency and equality in social care across Scotland, a disabled people-led organisation needs to be sustained in every IJB area, as a nation-wide investment. Their work needs to encompass:

- a. developing a 'pathways to independent living' programme, equivalent to Future Visions; and
- b. building and sustaining a user group to influence local and national social carerelated policy, comparable to the Social Care Expert Group.

For success, these organisations must be able to offer eight core elements. The first element (A disabled people-led organisation with statutory investment from the Scottish Government, commissioned to work with each local IJB on a sustainable basis) is what drives the title of this report: A Time to be Bold. In order to fulfil the ambition of collaborative reform of social care and to achieve the wider aim of the National Care Service to achieve consistency and equality in social care in every area of Scotland, a disabled-people led organisation needs to be sustained in every Integration Joint Board area, to lead a Future Visions-style programme. This needs to be a Scottish Government investment in disabled people-led groups to both drive fulfilment of independent living outcomes and provide a collective and ongoing voice into social care policy for disabled people, on local and national levels. The eight core elements are:

- 1. A disabled people-led organisation with statutory investment from the Scottish Government, commissioned to work with each local IJB on a sustainable basis.
- 2. A track record of removing barriers to disabled peoples' participation, understanding disabled peoples' lived experiences, and commitment to independent living.
- 3. Local knowledge and contacts and to be able to facilitate and sustain relationships with a wide variety of statutory, third sector and community stakeholders.
- 4. A holistic ethos, to be able to support diverse disabled people to actualise their preferred social care outcomes.
- 5. Disability equality and independent living expertise must be held in order to deliver disability equality training and independent living masterclasses to social care policy makers, service developers, service providers, and politicians.
- 6. Community navigation in the form of case work along with coaching approaches where needed for individuals using or needing social care.
- 7. Enabling peer support amongst disabled people using or needing social care.
- 8. A community development approach to build collective capacity enabling disabled people to participate in policy, practice, research, and leadership as a group.

2. Future Visions for Social Care

The Social Care (Self Directed Support) Scotland Act (2013) offers social care users four different options for SDS, ranging from a direct payment, to support arranged through the local authority, via a third sector organisation, or a mixture of these. The Self-Directed Support Act says that anyone who uses social care support services should have choice and control over the support they receive. However, research shows that SDS is yet to have a transformative effect on social care in Scotland, with low uptake of direct payments and with few users choosing to change provider (Audit Scotland 2017; Pearson et al. 2018; Pearson et al. 2020, p.287).

Led by GDA and funded by the Scottish Government, Future Visions initially aimed to:

1. Increase disabled peoples' knowledge and understanding of support options, including SDS.

2. Develop disabled peoples' skills and confidence to make informed choices, live a more independent and fulfilling life, and exercise greater choice and control.

3. Increase statutory services' understanding of the needs and experiences of disabled people, in order to plan and deliver holistic, person-centred solutions.

In the 2022-23 iteration of Future Visions, three distinct outcomes support and contribute to NCS co-design and the primary objectives of addressing the SDS implementation gap and testing models of prevention and early intervention support:

1. Codesign Action Research: disabled people are supported to codesign and test a model which builds understanding of rights and how to challenge where necessary to secure human rights, choice and control.

2. Research and Evidence: Future Visions data and evidence contributes to and informs NCS development, embedding a human rights approach to social care as an investment in disabled people and in wider society.

3. Collaboration and Codesign: local and national conversations draw on and work alongside key officials and Ministers, ensuring that codesign of the NCS model is informed by disabled people's lived experience.

Key learning from the consecutive and social care-related projects is outlined below. This is followed by an overview of the work of the <u>Social Care Expert Group</u> stemming from the programme. The report then makes an analysis of the eight core elements of Future Visions in enabling the work done and outcomes achieved, concluding that every IJB area in Scotland requires sustained Scottish Government investment to enable appropriate, local disabled people-led organisations to adapt the Future Visions model for local circumstances and so support disabled people to actualise independent living and to influence NCS and social care-related local and national policy.

a. My Choices: A vision for self-directed support (2012-2015)

My Choices was a Programme which was part of the first funded project, known as SDS Road Testers (2012-2015). This prototype for Future Visions was written up as an <u>Action</u> <u>Research report</u> (Witcher and participants, 2014) and further tested over the final year of the project. The purpose of 'My Choices' was to start with the vision for SDS, see what

could happen when disabled people were offered support to have choice and control over their lives, and find out about the sorts of support that they might need. There were sixteen disabled participants, ages 18 to 65, in three groups: younger people, employability, and older people. Participants had a wide range of impairments and/or health conditions, a diversity that has continued through all phases of Future Visions.

Using support, 'My Choices' participants were able to get out of the house, meet friends, do courses, improve their employability, experience better health and wellbeing, and improve relationships with family members, so overcoming isolation and typical barriers (2014, p.4):

'... the benefits of choice were clear to see. Some people's lives had been totally transformed... They had achieved things they (and others) had never thought possible.'

However, barriers to independent living remained, including poverty, risk of debt, benefit regulations, unmet needs due to eligibility limits, lack of preventative thinking by organisations, and physical, service and attitudinal barriers.

The project demonstrated that SDS can achieve independent living: 'There is overwhelming evidence that 'My Choices' did achieve the vision for SDS described at the start of this report.' (2014, p.5). Several core elements were essential to support people to make independent living choices:

- The co-ordinating role of the disabled people's organisation (DPO):
- The relationship with their Personal Assistant (P.A).
- The role of peer support.
- The importance of friends including friends made through the project.
- The importance of local knowledge and contacts.
- Timing sometimes rapid intervention, sometimes accommodating delay.
- The involvement of experts and specialists, as needed.
- The role of coaching in raising and sustaining aspirations.
- Trust in GDA as the co-ordinator of the project, related to GDA being led by disabled people, understanding the barriers facing disabled people, and having a history of tackling these.

This learning was taken into the second Future Visions project.

b. Future Visions 'Dare to Dream' (2015-2018)

This Future Visions project was written up by GDA as a <u>Future Visions Briefing Note</u> and a <u>Future Visions: Dare to Dream Summary report</u>. Hundreds of disabled people were engaged in the wider project and 43 participants received intensive support over this time. The project lasted 3.5 years as it received an extension after end March 2018 whilst GDA was being realigned to the national reform programme. Participants were drawn from different ages and stages in their life, and from different cultural backgrounds. Some had lifelong impairments and faced related barriers whilst others had opportunities and experiences prior to becoming a disabled person. The 2015-2018 programme included four core elements for participants:

• **Future Visions Information**: accessible information booklets; information stalls; support to telephone enquiries, emails and social media contacts; written materials;

films and events about Self-directed Support. This empowers people to know their rights, find support and access it.

- **Future Visions Life Coaching**: individual coaching sessions- a mixture of in person and by telephone depending on preferences, to help clarify goals and support participants to reach them. Working at participants' own pace, to safely explore barriers and develop aspirations.
- **Future Visions Peer Support**: group work to bring participants together to support each other, seeking to build confidence through sharing learning and experiences.
- Future Visions Tailored Support Plan: support and resources for individuals to plan and explore what will help them achieve their goal. Examples included: commissioning P.As for short periods to "try-out" directing support, buying specific technology/software, accessing learning opportunities, providing transport, offering opportunities to socialise and try new activities.

Before Future Visions, participants self-rated their quality of life as 2.6 out of ten on average; afterwards as 8.2 on average. Outcomes for participants included (FV Briefing Note, p.5):

- A more positive identity, sense of purpose, social connections and improved health and wellbeing.
- Accessing services and making choices, including social care and SDS.
- Accessing wider supports, including community-based supports and opportunities e.g. learning, training, volunteering and employment.
- Increasing independence: people were supported to participate more and be 'leaders' in their own lives, making contributions to their families, communities, and society.

A new element of the 2015-2018 project was to bring disabled people and planners, policy makers and decision makers together to share experiences and plan solutions. This later evolved into the Social Care Expert Group (detailed in e. below). GDA delivered events to highlight barriers and solutions to independent living as well as training and masterclasses.

Several core elements were essential to support people to make independent living choices:

- GDA's 'one stop shop' approach: connected participants to information, services, networks, campaigning and other activities and opportunities.
- Learning, coaching, peer support including role models raised aspirations, inspired change, and drove forward action.
- Access such as transport, personal assistance or communication support enabled participation.
- Building confidence and removing barriers are essential to changing mindset and setting goals.
- Disability Equality and independent living training for social care/SDS assessment and service providers, and related services e.g. housing, health.
- Building capacity, resilience and social connections transforms lives beyond the individual participants, to include family, friends and community.

- Simple assessment and a "good conversation" led to reduced red tape, built trust, targeted resources on self- identified needs and resulted in improved outcomes.
- Solutions were simple and included financial assistance, access, and personal support.
- Choice and Control developed identity, purpose and wellbeing.
- Feeling respected and being treated with dignity makes a difference.
- Solutions needn't cost a lot of money but do need to be flexible to make a big impact.

These core elements reinforced those found in the first project, SDS Road Testers and the *'My Choices'* Actions Research project and related report (2014). There were also strategic conclusions from Future Visions *'Dare to Dream'*:

- Lower-level, preventative supports, such as those modelled in Future Visions, need to be built into social care investment.
- Independent living outcomes, choice and control need to be emphasised within Commissioning frameworks.
- Disabled people need involvement in the design of social care (e.g. through Social Care Expert Groups).

c. Future Visions during Covid-19 (2020-2021)

Initially funded from 2018-2021, Future Visions had to change approach and respond differently during the pandemic. The Scottish Government along with other funders gave permission for GDA and other organisations to repurpose funds to meet need in relation to Covid-19 and the crises which the people of Scotland were facing - not least disabled people.

The Covid-19 period demanded a new Future Visions response with support for disabled people being provided through casework, equipment, resources and opportunities to participate in policy and co-design work via the Social Care Expert Group, including contributing to the IRASC consultation. Future Visions during Covid-19 included:

- Social Care policy influence: 227 disabled people signed up to contribute to ongoing social care discussions to feed into the Social Care Expert Group which had been established from 2018-2020 to embed lived experience in Adult Social Care Reform. During 2020, GDA supported disabled people to meet with Derek Feeley to contribute their lived experiences, ideas and priorities to IRASC.
- **Direct support for disabled people:** 128 people were given direct support to assist them to deal with social care issues, ranging from organising equipment, resources or practical assistance, through to emergency referrals and signposting, and combinations of all these in some cases.
- Future Visions model: 57 people received tailored one-to-one support through the existing project (during 2020-2021) which had been providing coaching, peer support and group CBT. Whilst advocacy support to unblock barriers to social care had been a previous strand of support, the supercharged inequalities due to the near collapse of social care in Glasgow and increased need through COVID-19, meant that the project "stepped-up" both individual and collective advocacy.

The other significant innovation of Future Visions during Covid-19 was the inclusive use of new technology to enable people that need or use social care to access the internet, and to

participate in online-only and hybrid Future Visions and Social Care Expert Group meetings and events. Removing barriers to technological participation enabled Future Visions involvement and contribution by disabled people to multiply.

d. Future Visions for Social Care (2022-2023)

Future Visions for Social Care (2022-23) is designed to develop the work of previous Future Visions programmes and the Social Care Expert Group. Again funded by the Scottish Government, it seeks to support disabled people who use or need social care to a. make steps towards independent living, and b. become involved in codesigning the National Care Service. Over 250 disabled people aged from 20s to 80s have taken part in the Social Care Expert Group, and the Future Visions programme has over 110 participants.

A tripartite model seeks to support disabled people to contribute to NCS codesign, and to continue to address the SDS implementation gap, whilst also testing models of prevention and early intervention support. The funding enables reasonable adjustments and removal of barriers to enable the Future Visions participants and Social Care Expert Group to convene at accessible venues, hybrid and online, supported by:

- a Policy and Participation Officer to support participants to codesign and test a model which builds an understanding of rights to Independent Living and to collectively influence and codesign policy, practice and service design;
- a Researcher to translate Future Visions and related findings into evidence to influence NCS development, SDS implementation gaps, and barriers to disabled peoples' participation and Independent Living; and
- a Community Navigator to provide practical and strategic support to disabled people facing challenging barriers to social care and independent living. They support individual disabled people to challenge and work through those barriers, support services to better enact social care to support those individuals, and feed learning from this work into the policy and participation conversations and research evidence. To date, the Community Navigator has supported over 110 disabled people, from teenagers to people over 90 years old.

Alongside these, Disability Equality Training and independent living input, including masterclasses at local and national levels, delivered by the GDA senior management team, have continued to influence politicians, policymakers and practitioners to work to remove barriers to independent living.

e. Future Visions for Social Care Expert Group

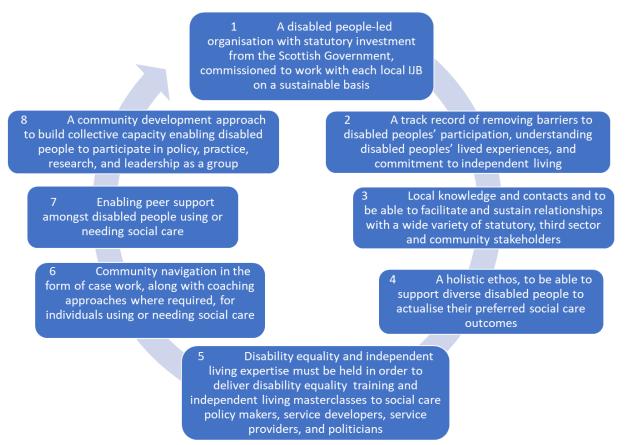
GDA's Social Care Expert Group works as part of the Future Visions model. Through peer support and capacity building activities, the Social Care Expert Group is supported by Future Visions to take part and contribute their lived experience to influence social care policy and decision-making at local (Glasgow) and national levels. From 2018 the Social Care Expert Group has helped shape the National <u>Reform Programme on Adult Social</u> <u>Care</u>, working alongside <u>Inclusion Scotland's People Led Policy Panel</u>. It played a key role in the <u>Independent Review of Adult Social Care</u>, sharing extensive lived experience of the social care crisis and its impacts on disabled peoples' lives before and during the Covid-19 pandemic. Since Covid-19, the Social Care Expert Group has widened participation by meeting online, hybrid, and in-person, with technological reasonable adjustments and

connectivity provided by GDA. It has then been able to meet in these new ways with local and national social care decision-makers including officials and politicians.

3. Analysis and recommendations: Future Visions for Social Care themes

GDA's Future Visions model, an investment by the Scottish Government, highlights the capacity-building role of locally-based Disabled People's Organisations in facilitating individual pathways to independent living and collective voice for people that need and use social care. The Future Visions approach can actualise the work to <u>reform adult social care</u> in Scotland, which is founded on supporting people to live independently, be active citizens, participate in society and maintain their dignity and their human rights. The aim of the National Care Service is to deliver independent living in all areas of Scotland through policies shaped by the voices of disabled people. To underpin this, a disabled people-led organisation - with values, networks and an approach comparable to that of GDA - needs to be commissioned in each of Scotland's Integration Joint Board areas to deliver a Future Visions for Social Care programme and Social Care Expert Group in every IJB in Scotland.

Drawing together the learning from the Future Visions iterations and the work of the Social Care Expert Group indicates the core elements that need to be incorporated, and adapted in each IJB where required, to successfully facilitate individual pathways to independent living and collective voice in policy for people that need and use social care. These are as below:



These core elements are expanded on below.

1. A disabled people-led organisation with statutory investment from the Scottish Government, commissioned to work with each local IJB on a sustainable basis. Via Future Visions, Scottish Government investment has enabled disabled people in the Glasgow region that need or use social care to have confidence that they can be supported to individually navigate towards independent living. Future Visions funding has also sustained social care policy influence by the Social Care Expert Group, both locally and nationally. In order to fulfil the ambition of collaborative reform of social care and to achieve the wider aim of the National Care Service to achieve consistency and equality in social care in every area of Scotland, a disabled-people led organisation needs to be sustained in every Integration Joint Board area, to lead a Future Visions-style programme. This needs to be a Scottish Government investment.

2. A track record of removing barriers to disabled peoples' participation, understanding disabled peoples' lived experiences, and commitment to independent living. Each local authority or IJB area will have its own configuration of organisations that have the strongest status, credibility, and history of removing barriers and collectively empowering disabled people, and people that need or use social care. This organisation needs to co-ordinate the Future Visions programme and Social Care Expert Group in each IJB area. The type of organisation that could potentially fulfil these roles within an IJB area would be most credibly filled by a disabled people's organisation (DPO), but in some IJB areas, centres for inclusive living, access panels, mental health user groups, or other organisations affiliated to the Scottish Independent Living Coalition will also have the necessary qualities.

3. The co-ordinating organisation also needs to have **local knowledge and contacts and to be able to facilitate and sustain relationships with a wide variety of statutory, third sector and community stakeholders**, being able to call on a variety of experts and agencies to support Future Visions participants. GDA already had a strong record as a DPO in supporting disabled people to do all sorts of things and to act as a broker to support people to engage with other organisations, including arts, education, employment, volunteering, research, health, community groups, culture, coaching and much more. GDA was therefore a credible organisation in practical terms to support disabled people with their Future Visions. The question again is which is the most effective organisation in each IJB with this established skillset?

4. The co-ordinating organisation must have a holistic ethos, to be able to support diverse disabled people to actualise their preferred social care outcomes. It needs to have the capacity, value-base and openness to consistently support people to go in their preferred Future Visions direction, at their own pace. This flexibility is almost unique to the third sector who do not hold the statutory responsibilities of the public sector, nor the profit motive of the private sector. However, the role is not 'neutral' and necessitates having the trust of disabled people, shared understanding of the barriers that face disabled people, and a commitment to independent living principles. This credibility is likely held by organisations run by-and-for disabled people, with lived experience central.

5. Disability equality and independent living expertise must be held in order to deliver disability equality training (DET) and independent living masterclasses to social care policy makers, service developers, service providers, and politicians.

DET and independent living masterclasses support staff personal learning, development and CPD to build understanding about disability and the disabling world, and independent living values and principles, specifically drawing on disabled peoples' expertise and lived experience. DET is different from 'disability awareness training' in that it is delivered by DPOs and disabled people, training politicians, leaders, assessors, providers and funders of social care, including the third sector, on barriers and solutions. The disabled people-led organisation coordinating Future Visions in each IJB area needs to be able to offer this, in order to achieve culture change in terms of social care strategy and delivery.

6. Community navigation in the form of case work, along with coaching approaches where required, for individuals using or needing social care. A community navigator can support people that need or use social care to negotiate barriers to social care and supports service providers to improve social care provision in response. Trained coaches help Future Visions participants to clarify goals and support them to reach them, working at participants' own pace to safely explore barriers and develop aspirations. For credibility, coaches for social care users usually need to have lived experience of being a disabled person or of using social care.

7. Enabling peer support amongst disabled people using or needing social care. Peer support enables social care users to get beyond individualised assessment practices that can hold back the potential of independent living. In a peer support arrangement, as in Future Visions, social care users can share experiences, ideas and ambitions with other disabled people, and confidence-build across the group. This also creates a new social network, so tackling the isolation that detriments the mental and physical health of so many disabled people. For success, it requires skilled facilitation by a person or organisation with an understanding of lived experience.

8. A community development approach² to build collective capacity enabling disabled people to participate in policy, practice, research, and leadership as a group, as with the Social Care Expert Group. Facilitating the collective voice of the group requires a community development approach: engaging, building capacity, and effecting change, creating a virtuous cycle. This will enable meaningful contribution to the NCS expectation of collaborative service design of social care at IJB and national levels.

Fulfilling these eight criteria, disabled people-led groups commissioned in every IJB area can adapt Future Visions for local circumstances, contributing towards fulfilling the policy and practice of independent living. Alongside this they can sustain collective voice and influence by disabled people both locally and nationally through an equivalent of the Social Care Expert Group. Through this work they will support social care providers and politicians locally and nationally to better deliver SDS and achieve independent living across Scotland.

² See <u>https://www.scdc.org.uk/who/what-is-community-development</u>.

4. Conclusion

Future Visions for Social Care suggests that Scottish Government investment in local organisations, already established and run by and for disabled people, should tangibly improve individual capacity for independent living, enable collective user involvement in social care policy and practice locally and nationally, and support the development of social care services. There is a need for such an organisation in every IJB area in Scotland. This investment needs to be a medium to long-term commitment.

Every IJB area currently has peer-led disabled people's groups. These may be Access Panels, Centres for Inclusive Living, social care user groups, mental health user groups and more. The appropriate organisation that can deliver the eight core elements, that embraces the values of independent living, and can capacity-build the voice of social care users, will differ in each IJB area.

Long-term investment in disabled people-led organisations to co-ordinate a Future Visions for Social Care programme and Social Care Expert Group equivalent in every IJB area is the 'how' of how to enable disabled people to actualise choice and control, independent living principles, and human rights obligations. This approach can support the Scottish Government to fulfil the call of IRASC (Scottish Government, 2021, p.21):

Throughout the report, we stress the importance of partnership and collaboration, and of amplifying the voice of staff and of people who need social care support. That is true at every level and in every part of the system... People with lived experience must be partners in the commissioning process and integral to decision-making and prioritisation, monitoring progress and making improvements; nothing about me, without me, as the saying goes.

The need for sustained Scottish Government investment to capitalise on the gains of the Future Visions for Social Care programme led by Glasgow Disability Alliance is what drives the title of this report: **A Time to be Bold**. In order to fulfil the ambition of collaborative reform of social care and to achieve the wider aim of the National Care Service to achieve consistency and equality in social care in every area of Scotland, a disabled-people led organisation needs to be sustained in every Integration Joint Board area, to lead a Future Visions-style programme. This needs to be a Scottish Government investment. A bold, strategic investment in disabled people-led groups will both drive fulfilment of independent living outcomes and provide a collective and ongoing voice into social care policy for disabled people, both locally and nationally.

References

Audit Scotland (2017) Self-directed support: 2017 Progress report. Available at: <u>https://www.audit-</u> <u>scotland.gov.uk/uploads/docs/report/2017/nr 170824 self directed support.pdf</u>.

Pearson, C., Brunner, R., Porter, T., Watson, N. (2020). Personalisation and the Promise of Independent Living: Where Now for Cash, Care and Control for Disability Organisations Across the UK? *Scandinavian Journal of Disability Research*, 22(1), pp. 285–295. DOI: <u>https://doi.org/10.16993/sjdr.742</u>.

- Pearson, C., Watson, N., and Manji, K. (2018) Changing the culture of social care in Scotland: Has a shift to personalisation brought about transformative change? Social Policy & Administration. DOI: <u>https://doi.org/10.1111/spol.12352</u>.
- Scottish Government, (2021) Independent Review of Adult Social Care. [online] Available at: <u>https://www.gov.scot/groups/independent-review-of-adult-social-care/</u>.
- Scottish Government (2022) National Care Service Statement of Benefits. Available at: <u>https://www.gov.scot/publications/national-care-service-statement-</u> <u>benefits/#:~:text=Published%2021%20June%202022&text=Sets%20out%20the%20</u> <u>benefits%20of,around%20its%20design%20and%20delivery</u>.
- Witcher, S. and participants (2014) My Choices: a vision for self-directed support. GDA: Glasgow.