Definitely maybe sometimes never

Prevention in adult social care – what does it mean to disabled people in Scotland?

A *Future Visions for Social Care* research report

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Executive summary

'... you wouldn't hit the crisis point if support was in place first...'

Scotland gives prominent policy emphasis to the social, economic and health benefits of prevention by public services (e.g. Christie, 2011; Scottish Government, 2025a) and to the principle that public services need a sustained focus on prevention (Scottish Government, 2025b, 2025c). The Feeley Review recommends a stronger focus on prevention activities in social care (Scottish Government, 2021).

Social care plays a vital role in society, and there will always be disabled people that need social care support to *'live in the community, with choices equal to others'* (UN Convention on the Rights of Persons with Disabilities, Article 19). However, there has been little focus on the practice of prevention in social care, and almost no attention paid to what disabled people using social care think about prevention as an idea, or about what prevention in social care means to them.

This 2024-25 *Future Visions for Social Care* research report from Glasgow Disability Alliance (GDA) and the University of Glasgow explores prevention in social care, combining (a) policy analysis, (b) evidence from the work of the GDA Community Navigator, and (c) findings from two innovative workshops with disabled people.

(a) There are four categories of prevention in public policy. This report applies these to social care as follows:

1. Foundational prevention – social care supporting partners that nurture strong communities and relationships (Build)
2. Primary prevention – social care trying to stop problems from occurring in the first place (Prevent)
3. Secondary prevention – social care trying to prevent further needs from developing (Reduce)
4. Tertiary prevention – social care trying to minimise the negative consequences of a problem (Delay)

Foundational and Primary are more proactive, or 'upstream', forms of prevention, Secondary and Tertiary more reactive or 'downstream'. In Scotland, the **SDS Framework of Standards** (updated May 2024), which frames prevention as *'early help'*, and the Scottish Government-COSLA Joint Statement of Intent and Next Steps for Adult Social Care 2022-23 (Dec 2022, p.6), which foregrounds *'prevention, early intervention and anticipatory care'* align with social care-related services focusing on proactive or 'upstream' prevention.

(b) The role of the GDA Community Navigator (CN) is to support disabled people to overcome barriers to getting the social care they need, and to support social care-related services to remove those barriers. All CN cases exist because of lack of effective prevention by social care-related services; the 'voice' of disabled people that need social care has not been heard, or has been heard but not effectively responded to. The CN amplifies disabled peoples' voices through advocacy or supporting self-advocacy.

The report makes an in-depth analysis of eight CN cases (Appendix 1), each of which demonstrates (i) the complexity of lives in which prevention interventions in social care often need to work; (ii) the extent to which the CN's interventions were able to succeed; (iii) the prospective service costs and prospective consequences for the individual resulting from social care prevention not happening. The analysis finds:

- How the CN prevents lack of 'voice' by disabled people – a category of prevention that underpins all four current policy categories.
- That the CN cases rarely fit into a neat box labelled 'social care' and require the CN to engage with other, social care-related services, notably health and housing. This is consistent with the Scottish Government-COSLA Joint Statement of Intent and Next Steps for Adult Social Care 2022-23 (Dec 2022, p.6):

  > Preventative approaches go beyond the boundaries of social care and health services. Housing, economic growth, education, leisure, community development, are all essential in delivering joined-up public health approaches to prevention and wellbeing.

- The potential benefit for services in 'front-loading' prevention at the proactive stages (Foundational and Primary), the prospective service cost of lack of preventative action, and the prospective service costs averted due to the work of the CN.
- How lack of prevention by services can not only negatively affect the wellbeing of disabled people, but also their family/friends.
- That overwhelming demand for CN support suggests that there are persistent examples of social care-related services not being sufficiently preventative.
- That the CN approach of 'listen-advocate-check' is a potential model for how social care-related services could also operate to maximise successful preventative action.

(c) Two innovative workshops about prevention policy, practice and experience were held in 2024-25 with disabled people that either need or use social care. Analysis of findings shows:

- That social care-related services should be acting to prevent a lack of 'voice' by people needing or using social care. A duty on social care-related services to prevent lack of voice should be an underpinning feature of all four prevention

categories – without voice, prevention won't happen. This is consistent with the 'lack of voice' gap identified in the work of the CN and is consistent with the Social Care (Self-Directed Support) (Scotland) Act 2013 four statutory principles for SDS: participation and dignity, involvement, informed choice, and collaboration. Those principles are designed to ensure individuals receive support that respects their human rights, prevents disempowerment, and allows them to make choices about their social care.

- To prevent lack of voice for people using or needing social care, social care-related services should be funding Disabled People's Organisations (DPOs), advocacy services and other arms-length 'voice' organisations that nurture strong communities, including communities of identity. This would bolster Foundational prevention in social care.
- Lack of proactive prevention can stop disabled people from having a social life and from being able to sustain independent living, with costly impacts on their physical and mental health and wellbeing. This is the opposite of prevention.
- To deliver proactive prevention at Primary and Foundational levels, social care needs to be far more porous and 'open-door', with community level access and 'routes in'. Social care needs to be non-stigmatised, like a school or drop-in.
- When social care-related services act preventatively, there can be a 'double' prevention benefit; it can also prevent family members/friends of the social care user from risking their wellbeing by trying to support someone for whom more formal social care is needed or preferred. It also prevents friends and family from becoming carers against the wishes of the disabled person.

Conclusion

- A practice shift by social care-related services from reactive (Secondary and Tertiary) to proactive (Primary and Foundational) prevention is more strongly in line with public policy in Scotland. This shift will better support the social care needs, and therefore the wellbeing, of disabled people in Scotland, and in turn their friends and families.
- 'Voice' underpins all four prevention categories. It is the role of social care-related services to maximise and respond to voice, both through the way they organise their own services and by funding DPOs and other organisations that enable the individual and collective voice of people needing and using social care.
- A more porous, 'open door' approach, and normalisation of social care use would support the shift to proactive prevention.
- Disabled people can participate in research seeking to improve prevention by social care-related services. More systematic research on disabled peoples' experiences of prevention in social care is needed.

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All *Future Visions for Social Care* research reports are available at: https://www.gla.ac.uk/research/az/centrefordisabilityresearch/work/collaborationwithglasgowdisabilityalliance/.

1. Introduction

'... you wouldn't hit the crisis point if support was in place first...'

There is a strong policy emphasis in Scotland on the social, economic and health benefits of prevention by public services (e.g. Christie, 2011; Scottish Government, 2025a), and on the principle that public services, including health and social care, need to sustain their focus on prevention (Scottish Government, 2025b, 2025c). But there's little discussion about what prevention means in the context of social care, or what it means to disabled people that need or use social care. As part of the *Future Visions for Social Care* (FVSC) programme, University of Glasgow and Glasgow Disability Alliance (GDA) have done some work to understand this. This report synthesises policy analysis, evidence from the work of the GDA Community Navigator (CN), and themes from two workshops with disabled people in need of or in receipt of social care. We hope that the evidence will improve social care policy and practice on prevention, and so support disabled people to be able to better achieve independent living outcomes.

a. Who should this report be useful to?

This evidence informs the Scottish Government, Health and Social Care Partnerships (HSCP), Integrated Joint Boards (IJB), social work/social care teams, and leaders in social care-related services, about how they might develop their thinking about both the theory and practice of prevention in social care. It informs Disabled Peoples' Organisations (DPOs) about what prevention means to disabled people. It informs researchers about emerging themes for more systematic study. The report offers evidence about how prevention can and should be used more proactively to serve social care needs, improve outcomes, and address inequalities.

b. What is *Future Visions for Social Care*?

Funded by the Scottish Government since 2012, GDA's *Future Visions for Social Care* (FVSC) programme combines two elements that operate at the level of prevention.

First, the GDA Community Navigator (CN) supports disabled people, especially those that are most marginalised and who lack 'voice', to navigate barriers to social care. This enables social care-related services to address needs that have not been prevented. CN interventions work across multiple areas of concern including: social care, social work, housing, health, advocacy, welfare, digital exclusion, and wellbeing support. When successful, the interventions of the CN lead to: better social care outcomes, better healthcare for marginalised disabled people, and better relationships with social care-related services for disabled people. The CN's work supports social care-related services to hear the voice of people needing social care, and so to be able to 'do prevention better'. The need for CN advocacy mainly arises because services have not prevented problems arising for disabled people needing social care-related support.

Second, FVSC has a Social Care Expert Group (SCEG) that collectively organises disabled people. This seeks to prevent disempowerment by enhancing disabled peoples' collective 'voice' in influencing policy. By bringing disabled people together, SCEG also prevents isolation among disabled people.

These two strands of FVSC lend themselves to finding evidence to support social care-related services in Scotland to re-animate the meaning of prevention as a mode of empowerment and inclusion, and to be able to activate prevention more proactively.

This report synthesises learning from these two elements of FVSC. Section 2 analyses eight examples of prevention from the work of the Community Navigator, presented in full at Appendix 1. Section 3 presents findings from two innovative workshops held with a sample of SCEG members using and needing social care to gain a 'lived experience' understanding.

c. What does prevention mean in social care?

This section draws together prevention theory, policy and practice knowledge, to clarify how to best think about prevention in social care in Scotland. Historically, evidence on prevention in social care is slim for various reasons, including: lack of shared understanding of what prevention is; difficulties in demonstrating cause and effect; and the long timeframes needed for measurement (Social Care Institute for Excellence, May 2021).

i. Prevention in theory

In public policy, prevention has traditionally been subdivided into three categories: primary, secondary, and tertiary (e.g. O'Brien and Charlesworth, 2024; Tew, Duggal and Carr, 2025). Applying prevention theory to social care, SCIE (May 2021) re-interprets the three categories as prevent, reduce, and delay. This takes policy-focused understanding of prevention beyond the apparently simple notion of prevention as stopping problems from occurring.

However, O'Brien and Charlesworth (2024) find that primary, secondary and tertiary levels of prevention do not cover another level of prevention - foundational prevention (sometimes called primordial prevention in health settings). At this foundational level, Curtis, Glover and O'Brien (April 2023) find that local, social and civic infrastructure also play a critical role in prevention, fostering social capital which supports population health. These community partners, such as drop-in centres, user-led organisations, employment and educational support, are all part of the social care nexus. Social care benefits from these infrastructures being strong.

Applying this framework leads to four categories of prevention in social care (Table 1):

Table 1 – four categories of prevention in social care	
Prevention category	**Examples**
1. Foundational prevention – social care supporting partners that nurture strong communities and relationships (Build) • Local, social and civic infrastructure, often operated by actors outside of the state, focused on long-term prevention. These institutions cultivate social capital which supports population health.	Drop-in centres, support for user-led organisations, employment and educational support.
2. Primary prevention – social care trying to stop problems from occurring in the first place (Prevent) • This approach should be applied to everyone, encompassing a range of services, facilities and resources that will help avoid the need for care and support developing.	Information and advice, promoting healthy and active lifestyles, reducing loneliness and isolation.
3. Secondary prevention – social care trying to prevent further needs from developing (Reduce) • Targeted at individuals at risk of developing needs where support may slow this process through early detection and intervention.	Falls prevention, housing adaptations, support to manage money.
4. Tertiary prevention – social care trying to minimise the negative consequences of a problem (Delay) • Aimed at people with established complex health conditions, to minimise the effects, support them to regain skills and to reduce their needs wherever possible.	Rehabilitation/reablement services, meeting a person's needs at home, providing respite care, emotional support and stress management.

Primary and Foundational are more 'proactive' prevention; secondary and tertiary are more 'reactive' prevention (or 'upstream' and 'downstream' (Scottish Government, 2025, p.11). These four categories were tested at Workshop Two with SCEG members, as analysed in Section 3b, below.

ii. Prevention in practice: social care policy in Scotland

The Christie Commission (2011) called for a decisive shift towards prevention by public services in Scotland, recommending (2011, p.ix): *'Prioritising preventative measures to reduce demand and lessen inequalities.'* In the context of social care, the Feeley Review (Scottish Government, 2021, p.4) argued for a move from *'old thinking'*, such as social care being perceived as available in a crisis, to *'new thinking'* with social care becoming preventative and anticipatory. Feeley's recommendations specified this further, consistent with prevention in the Foundational and Primary categories (Table 1, above):

> Recommendation 3: People must be able to access support at the point they feel they need it, including for advice and signposting to local community-based resources and help, and for barriers to this, such as the current eligibility criteria

and charging regime, to be fundamentally reformed and removed, to allow a greater emphasis on prevention and early intervention.

Recommendation 6: Informal, community based services and supports must be encouraged, supported and funded to respond appropriately to the needs of local citizens, including for preventative and low level support.

Self Directed Support (SDS) is Scotland's primary vehicle for delivering social care support. Again consistent with the focus on the Foundational and Primary categories of prevention, in the **SDS Framework of Standards** (updated May 2024) prevention is framed as *'early help'* (Standard 2: Early Help, Family Support and Community Support), reproduced in Table 2:

Table 2 – SDS Framework of Standards (updated May 2024, Standard 2)
Standard 2 descriptor: Early help, family support and community support are available to all people who need it. Practice statement: Providers of early help, family support and community support offer approaches where everyone is welcome to have a conversation about what matters to them, and to identify solutions to improve wellbeing. Core Components: 2.1 Early help, family support and community support are available to meet a range of needs before becoming critical. This helps to maintain people's independence and wellbeing, addressing loneliness and social isolation and helps people to feel connected. 2.2 Supports identified build on a person's own strengths, talents and assets, wider family and natural networks, technological and digital supports and community resources. 2.3 Early help, family support and community support give people and communities a voice, and support the trusting relationships that are needed to co-produce the care and support that people want. 2.4 Early help and community support is creative and responsive, and is adaptive to changing circumstances.

Standard 2 is clear that *'everyone is welcome to have a conversation about what matters to them'* i.e. that SDS is universally accessible, supporting peoples' needs at the earliest stage. Like Feeley, the SDS Standards again align with the Foundational and Primary categories of prevention - social care trying to stop problems from occurring in the first place, and supporting partners that nurture strong communities.

These expectations of prevention are also consistent with the Scottish Government-COSLA Joint Statement of Intent and Next Steps for Adult Social Care 2022-23 (Dec 2022, p.6) section on prevention:

> The Scottish Government and COSLA share a strong desire to improve care for people across their life by continuing to embed prevention, early intervention

and anticipatory care, with ongoing co-design and human rights at the heart of the approach.

There is a consensus in policy that social care in Scotland should focus on prevention to proactively address needs, and to seek to stop problems from occurring in the first place. This might be, for example, by social care funding and supporting Foundational partners that support strong social relationships, and by social care and related services maximising Primary prevention or 'early help' in their own right.

Prevention is commonly talked about in the abstract, with little reference to what disabled people needing or using social care think about prevention as an idea, or about what prevention means to them in practice. The next sections draw out disabled peoples' experiences and voices through analysis of the work of the GDA Community Navigator (Section 2) and through two workshops with disabled people using or needing social care support (Section 3).

2. How does the GDA Community Navigator support prevention in social care?

The role of the GDA Community Navigator (CN) is to support disabled people in the Glasgow region to overcome barriers to getting and/or utilising the social care they need, and to support social care-related services to remove those barriers. Most people the CN supports have a combination of services they interact with, and diverse barriers to getting the support they need. Between April 2022 and March 2024, 57% of people supported by the CN had no social care in place at all (Brunner, McAloon, Scobie, and Burke, 2024). The CN also supports disabled people that *do* receive social care and SDS but need more of it to *'participate in society and live a full life'* (Scottish Government, 2021, p.9) and so to actualise SDS and its intention of supporting independent living. The CN enables 'voice' by advocating to services on the individual's behalf, or by supporting self-advocacy. For services, the CN's interventions support them to reactively tackle peoples' needs that were not proactively prevented.

This section sets out how the work of the CN prevents lack of 'voice' by people needing and using social care, and how their work illuminates how social care-related services could do prevention better, including by averting future service costs due to inadequate prevention.

Disabled people contacting the CN have social care needs that have not been prevented from occurring, at one, two three or all four of the prevention categories (Table 1). Some may not know how to navigate services to get their voice heard, an assessment made, and their needs met. Others may be on a waiting list for an assessment or services, their social care needs still not being prevented.

The cases that the CN supports rarely fit into a neat box labelled 'social care'. The CN engages with other public services, notably health and housing (Brunner, McAloon, Scobie, and Burke, 2024), as part of seeking to prevent disabled peoples' social care needs from not being met. This is consistent with the Scottish Government-COSLA Joint Statement of Intent and Next Steps for Adult Social Care 2022-23 (Dec 2022, p.6) section on prevention:

> Preventative approaches go beyond the boundaries of social care and health services. Housing, economic growth, education, leisure, community development, are all essential in delivering joined-up public health approaches to prevention and wellbeing.

Eight Community Navigator prevention cases from 2023-24 and 2024-25 were collated by Fiona McAloon (GDA Community Navigator) and Dr Richard Brunner (University of Glasgow). The eight anonymised cases are described in full at Appendix 1, based on the CN's contemporaneous records, with minor editing for clarity. They show how the CN enables prevention by social care-related services, and demonstrate the complexity of lives in which prevention interventions in social care need to work, in which being a disabled person can be merely one issue of many. They therefore offer a stimulus for analysis of prevention realities in social care. The sample are a range of types of case and are not selected for 'success' or with any claim of representativeness. As there is little prior evidence of the role of community navigation in enabling disabled peoples' voice in prevention, they act as a forerunner for more systematic study.

All eight cases have disabled people using or needing social care at the centre. Each person or family requires a specific configuration of social care support to enable them to live independently and prevent them from having unmet needs (Zarkou & Brunner, 2023). At best, prevention gaps constrain people in each case from sustaining independent living, and at worst place their lives at risk. The eight cases show the consequences of inadequate prevention. The eight cases (Appendix 1) are:

i. Prevention of multiple health risks through replacement of a broken hoist.
ii. Preventing a persecuted disabled person living in a property with an inaccessible toilet from having to continue in the same situation.
iii. Prevention of sepsis, pain and further limited mobility.
iv. Seeking to prevent lack of post-hospital discharge social care support.
v. Prevention of a person with learning disabilities becoming homeless and at risk.
vi. Preventing a bullied disabled child from being excluded by the education system, and preventing their parent from illiteracy.
vii. Prevention of homelessness, drug relapse, criminal justice use, and the need for social work and social care intervention and support.
viii. Prevention of risk of a disabled person being hospitalised, being in debt and committing crime, related to substance addiction.

The eight cases highlight the following prevention themes:

a. They all demonstrate how the CN prevents lack of 'voice' by disabled people in need – a category of prevention that underpins all four policy categories (Table 1, above). It is not the job of the CN to 'do' prevention. It is public services' job to 'do' prevention. Sadly, all CN cases exist because of lack of prevention by social care-related services, including because the 'voice' of disabled people that need social care was not heard, or was heard but not effectively acted upon. This gap is inconsistent with the Scottish Government-COSLA Joint Statement of Intent and Next Steps for Adult Social Care 2022-23 (Dec 2022, p.6) point that:

> … to support a preventative approach, people must have a strong voice in planning their own care. Their strengths and needs must be at the centre of the approach throughout, regardless of what services people interact…

The cases show how the CN amplifies those voices through advocacy or supporting self-advocacy, through helping disabled people to navigate service systems, and by working with those services to reactively put the needed support in place.

b. All eight cases indicate the potential outcomes for the person, and the type of social care-related needs that would have plausibly arisen had the CN intervention not been made. These needs are a cipher for the 'service cost' of lack of prevention – they signify the prospective services that would have likely soon been needed, and so the prospective service costs that were averted because of the CN's interventions. This also signals the likely multiple benefits for services in 'front-loading' prevention at the proactive stages (Foundational and Primary), as SDS policy, and the Scottish Government-COSLA Joint Statement of Intent and Next Steps for Adult Social Care 2022-23 (Dec 2022, pp.6-7), suggests they should.

c. All cases show the sometimes-shocking consequences of lack of prevention. These include risk to the person, including at a life-and-death level, ranging across: injury to self and others (case i), distress and harassment (ii), skin integrity (iii), safe discharge from hospital (iv), homelessness and exploitation (v), school exclusion (vi), homelessness, drug relapse and potential criminal justice use (vii), and hospitalisation, crime and debt (viii). These indicate the escalating consequences that can arise if services have not prevented needs from being adequately met, or not met in a timely fashion.

d. Some cases demonstrate how inadequate prevention by services also has impacts on the wellbeing of the family/friends of the disabled person, including due to 'loading' the risk for managing a situation that needed preventing by services onto family, friends, or flatmates (cases i, iv, v, vi). Some show the potential for wider negative impacts of lack of prevention on communities (cases ii, vii, viii). If prevention does not happen, the ripple effects can go far beyond the individual needing support.

e. All cases state the categories of prevention at which the CN is intervening (Table 1). Although each example has unique features, for six of the cases (i, iii, iv, v, vii, viii) the CN is intervening for experiences that are in the Tertiary (minimising negative consequences) and Secondary (preventing further needs from developing) categories. These are the most reactive end of social care prevention, where problems are happening already. Only one case (vi) involves Foundational work, activated by the CN. It is important to note that Foundational and Primary prevention may be successfully activated all the time by social care-related services – those cases would tend not to reach the CN, and so are not part of this sample. But the overwhelming demand for CN support at the reactive end does suggest that gaps in proactive prevention by social care-related services are significant; from April 2022 to March 2024, the CN worked with 242 people, making a total of 869 interventions (Brunner, McAloon, Scobie, and Burke, 2024).

f. While some cases are ostensibly simple, they still tend to require the CN to liaise with two or three services to seek resolution, e.g. cases (i) social work, occupational therapy and district nursing, (ii) housing department, housing options for older people, and Glasgow Centre for Inclusive Living (iv) social work and a hospital discharge team. This reinforces the need for social care-related services to be working together to activate prevention (Scottish Government-COSLA Joint Statement of Intent and Next Steps for Adult Social Care 2022-23, Dec 2022.

g. All eight cases involve the CN actively listening to the disabled person and/or their family, to understand the social care-related need. The CN then enables 'voice' (advocacy or self-advocacy) through the process. Finally, the CN checks whether the need that has been advocated for has been satisfactorily met from the disabled person's point-of-view. Listen-advocate-check is a potential model for social care-related services to draw out voice and satisfactorily secure prevention.

The CN prevents lack of 'voice' by people needing and using social care. Their work illuminates how social care-related services could do proactive prevention better. This could be through using a listen-advocate-check model; enabling voice, including through supporting DPOs and other Foundational organisations; and by social care-related services working better together, reflecting the complexity of peoples' lives. The evidence shows the service costs and complications that emerge if Foundational and Primary prevention do not happen: needs not being met, which can be catastrophic for disabled people; ripple effects on families and communities; and building up future service costs. Policy is clear that proactive prevention, or *'early help'*, is expected; the CN evidence reinforces the benefits of this for people and services alike.

3. What do disabled people say about prevention in social care?

As there is little evidence of disabled peoples' views and experiences of prevention in social care, the FVSC Researcher (University of Glasgow) and FVSC Policy and Participation Coordinator (GDA) devised and facilitated two workshops for GDA SCEG members either in receipt of or needing social care support. Holding two activities improves the credibility of interpretation of themes (Spencer et al, 2003), allows more accountability to participants, and enables a move from dialogue to deliberation (Escobar, 2011).

In Nov 2024, 12 disabled people attended Workshop One: six who received social care, and six who did not receive any social care, but felt they needed it. Participants were aged from 20s to 70s and had experiences from a range of local authorities. A 'metaplan' exercise was used to elicit, capture and theme participants' experiences of prevention in social care. The same participants were invited to Workshop Two, with six people attending, and discussions focusing on the four categories of prevention (Table 1, above) and an exercise asking people to consider whether social care should definitely, maybe, sometimes, or never be playing a role in a sample of issues consistent with typical prevention themes tackled by the GDA Community Navigator. Participants were offered £25 vouchers for being involved in each workshop. Notes were taken throughout for analysis.

a. Workshop 1 (Nov 2024)

The metaplan exercise drew out several themes on what disabled people want, and what they get, from social care in terms of prevention. Participants were separated into two groups: (a) receiving social care (6 people) and (b) needing social care (6 people). Individuals were asked to write on post-its three examples of (group a) 'What does your social care package actually prevent from happening to you?' and (group b): 'What would you want a social care package to prevent from happening to you?' Each group clustered their responses (Fig. 1) and devised a title for each cluster. Tables 2 and 3 reproduce each group's cluster titles and participants' words as written on the post- its.

Figure 1	
Group a – receiving social care	**Group b – needing social care**
	

(i) Group A: Receiving social care

Table 2	
Cluster title	**Prevention of… (words written on post-its)**
Health inequalities and Pressure on the system.	a. Cleaner house … prevents disease? b. Falls. c. I haven't had a hospital admission in 2 years.
Wellbeing/mental health	a. prevents me having to stay in bed all day/wellbeing/mental health b. I can maintain relationships without extra strain of them caring for me c. Since holistic support I've gone 4 years without a mental health crisis – first time in 17 years.
Lack of practical support for essential tasks	a. Form filling and reading. b. Prevent laundry being dirty. c. Prevent me from having to live in my pyjamas.
Social isolation/loneliness	a. Gives me contact with the outside world through conversations with the carer (if they speak to me). b. Prevent me from being in bed all day. c. Prevent house being unclean and untidy [which avoids] not wanting people in, staff not allowed in.

Interpreting these using the four categories of prevention (Table 1, above):

• Foundational prevention: social care supporting partners that nurture strong communities and relationships.

- Examples: holistic support with mental health, enabling people to separate friends from carers and so maintain friendships.

• Primary prevention: social care trying to stop problems from occurring in the first place.

- None.

• Secondary prevention: social care trying to prevent further needs from developing.

- Reducing risk of hospitalisation through interventions to prevent falling.

• Tertiary prevention: social care trying to minimise the negative consequences of a problem.

- Examples: practical support with form filling, reading support, washing clothes, cleaning the house and getting dressed (allowing sociability/preventing isolation), preventing people having to stay in bed, support with cleaning the house (disease management).

The experience of those receiving social care was of social care mainly operating at Tertiary prevention level (trying to minimise the negative consequences of a problem). It indirectly offered some Foundational prevention (e.g. enabling people to maintain friendships), with one example of Secondary prevention. This suggests that for the group receiving social care, social care generally offered reactive, rather than proactive prevention, missing opportunities for *'early help'* (SDS Framework Standard 2).

(ii) Group B: Needing social care

Table 3	
Cluster title	**Prevention of… (words written on post-its)**
Prevention of isolation and exclusion	a. Getting lost or confused when I am out in the community b. Subscription to activities (paying); referral to social groups; befriender c. social care help would mean I would be able to get dressed and showered every day – rather than staying in my pyjamas day after day
Preventing lack of housing choice	a. Prevent living in inaccessible housing b. Prevention of an institutionalised, unfit system
Preventing health risks and/or deterioration of health	a. prevent from falling in the shower and struggling to shower. b. support me with personal care; risks of slips and falls. c. Prevent poor health in future by putting measures in place now (personal helper when in crisis) d. social care to help with housework as this causes over exhaustion and pain getting worse – I cannot pay people to do this for me
Prevention from discrimination	a. Prevention of stigmatisation b. Prevention against discrimination in education and the workplace. c. Prevention of inequality

Prevention from losing human rights and prevention of disempowerment	a. Prevention of not getting the information b. prevention of not being in charge. Prevention of disempowerment
Prevention of mental distress	Prevention of bad mental health (support worker taking me to gym etc. or outing)
Prevention from having too much responsibility	Feeling responsible for all basic tasks like shopping for my whole family
Prevention of poverty and unemployment	a. social care help would mean I could get a job and my life would be better financially and I would have a positive purpose in life. I would love a work from home job.

Interpreting these using the four categories of prevention (Table 1):

• Foundational prevention: social care supporting partners that nurture strong communities and relationships.

- Examples: subscribing to activities, referring to social groups, befriending, prevention of stigmatisation, discrimination in education and the workplace, and prevention of inequality.

• Primary prevention: social care trying to stop problems from occurring in the first place.

- Examples: taking to the gym, preventing poor future health through providing personal help now.

• Secondary prevention: social care trying to prevent further needs from developing.

- Examples: preventing people from being expected to move into institutions, preventing people having inaccessible housing, reducing health deterioration/risk of hospitalisation through interventions to prevent falling.

• Tertiary prevention: social care trying to minimise the negative consequences of a problem.

- Examples: helping people get dressed and showered, help with housework, helping people to not get lost or confused when out, prevent people having to stay in bed, support with personal care.

The experience of those not receiving social care was of wanting prevention to operate across all four levels. While at Tertiary level, their expectations were similar to the group receiving social care, at Foundational level there was a breadth identified by this group that was strikingly wider - enabling people to maintain social activities, preventing

stigmatisation, tackling discrimination in education and the workplace, and preventing inequality. Unlike the group already receiving social care, this group also specified social care support needs in the Primary category and more in the Secondary category. This suggests a potential gap between what disabled people that need social care want it to proactively prevent happening, and the reactive levels at which those using social care currently experience it. This was explored further at Workshop Two.

The group not receiving social care also identified a new category of prevention that does not fit neatly within the four policy categories: *'Prevention from losing human rights and prevention of disempowerment'* (Table 3, above). Examples were not getting information, not being in charge, and being disempowered. This theme is not apparent in the prevention literature. In Scotland the Social Care (Self-Directed Support) (Scotland) Act 2013 established four statutory principles for Self-Directed Support (SDS): participation and dignity, involvement, informed choice, and collaboration. These are inextricably connected to 'voice', a feature that the GDA Community Navigator enables (Section 2, above). The CN findings demonstrated how disabled peoples' voice is not always heard by social care, hence prevention needs arise. This suggests that a duty on social care-related services to prevent lack of voice by people needing and using social care, should be an underpinning feature of each of the four prevention categories – otherwise prevention won't happen. This workshop, eliciting disabled peoples' voice on prevention, raises this important new consideration.

It is notable that prevention of disempowerment or 'voice' was not suggested by the group receiving social care. Here, adaptive preferences (Sen, 1992) may play a role, with people narrowing their expectations based on their lived experience of social care prevention. As one Group A participant noted:

> Keen to emphasise for myself and other disabled people, we adapt and amend our lifestyle … effectively its quite a disabling existence. In terms of day-to-day cooking and eating, you don't do it that's fine … social services, social work you are not a priority. They don't think about the debilitating health inequalities.

(iii) Whole-group discussion

The groups read each other's clusters and were asked what they noticed. Group A felt the other group *'looked at concepts, like prevention of bigger things. Such as disempowerment, inequality etc.'* Members of both groups identified commonalities around preventing falls, prevention of staying in bed all day, and the importance of preventing isolation. A Group B member, reflecting on the limited prevention realities of those receiving social care in Group A, noted: *'I thought it would be littered with positives'*, a Group A member responding: *'Experiences have lowered our expectations. To what social care can prevent. Or what they are willing to give.'* One participant reframed the focus of prevention to social services: *'Preventing low expectations from social work.'* The risk is that social workers and related professionals, and the

structures within which they work, also internalise adaptive preferences (Sen, 1992) leading to lower expectations of disabled people and potentially missing opportunities for prevention at Foundational and Primary levels that will help disabled people get the preventative support they need to maintain independent living.

The need for listening and empowerment by social workers was an emerging theme: *'It's about listening to the person - can support liberation'*; and *'Knowledge is power in a way, I'm still finding my feet. You don't know what you don't know'*. Eliciting voice is not solely the job of services, though; one participant noted that GDA had supported them to get information about social work. There is a vital role for independent NGOs and DPOs in the prevention of disempowerment and preventing lack of voice across all four prevention categories. This theme was highlighted further at Workshop Two.

b. Workshop 2 (Apr 2025)

The same SCEG members were invited to participate, with six people attending – three receiving social care, three needing social care. Two exercises built on Workshop One.

(i) Exercise 1 – the four categories of prevention

This exercise sought to understand what disabled people think of the four categories of prevention as used by policymakers. Participants were given a sheet replicating Table 1 (above), and this was talked through by Dr Brunner:

> Prevention is seen by policy-makers as a more complicated thing than just stopping something happening before it happens. But it also means early detection of a problem. And then it means that the problem might already be happening and it's trying to stop it getting worse. I just wondered is there any reflections on what I've just described? Because I don't think disabled people or people using social care have had any say over these categories of prevention.

Discussion included the following three comments:

> There is nothing there about ask or listen to the person that's speaking to you.
>
> … you're living in a world, which is full of barriers and chaos and you go there and maybe … you're really try to find a quick fix for that one. So you go there. You go to them who allegedly are a trusted resource in terms of support, advice, et cetera. And ultimately, when you get there you're faced with bureaucracy, barriers, time constraints, and … they put the onus on yourself to instigate it… Rather than social services, health and social care taking it and then negotiating, they then put the onus back on yourself.
>
> I've had experience with social work many years, not just for myself, my brother growing up, and there was never primary prevention. They always step in at the

> secondary prevention. There's never any of that, information, advice, promoting healthy lifestyle stuff … if that is done, it's done by your GP, through the sort of like community workers, whatever.

Participants' experience was that social care tends to intervene reactively, and tends to responsibilise people that approach them. People felt that social care needs to be more proactive in raising and attending to needs at the Primary and Foundational stages and needs to enable and respond to 'voice'. These go together; eliciting voice is the basis for social care to be able to be proactive and deliver *'early help'*, *'where everyone is welcome to have a conversation about what matters to them'* (SDS Standard 2).

How a person's problems and impairments can escalate when preventative interventions are removed was demonstrated vividly by a participant, who was also an asylum seeker:

> … there are disabled people with asylum problems that really need the support of the social care. When I had an operation, there was somebody to take me out all the time, but then they stopped my support and then the person never turned up anymore. So the social service never did anything. I was abandoned for five years in the house. Nobody was taking me out, nobody was taking care of me. And then I end up with other diseases like diabetes and high blood pressure and then depression.

Lack of prevention across all four categories had costly impacts on this person's physical and mental health – the opposite of prevention.

The importance of social life to wellbeing, and how social care needs to act to prevent disabled people from not being able to have a social life was also discussed:

> I don't have a social life. I have to accommodate the carers coming in when it suits them to come in. And all they're there for is personal care. They're not there to help me get out into the community or to do any of the activities that I want to do. Even getting here this morning, that takes three phone calls to make sure somebody's there in the morning to let me out to come here.

Delays in assessment and provision of support can also be a barrier to prevention, as another participant argued:

> … with myself, things can change in the matter of hours. So like in the space of a year, if you're waiting for an assessment, how much can change from when you first had that discussion to when an assessment actually happens?

The importance of equipment breakdown being prevented by regular servicing was also highlighted: *'Some equipment breakdown, it's gonna happen with age, but it's when that happens, it becomes an emergency.'* This example also demonstrated how social care support can prevent injury to others supporting the disabled person:

> Fiona [GDA Community Navigator] helped me get my hoist replaced… And that isn't only important for my safety and prevention, skin breakdown, everything, but also for the safety of my unpaid carer.

This prevention benefit applies to family members and flatmates of disabled people, who may risk their own wellbeing by stepping in to provide support when a person is on a waiting list, has equipment breakdown, or does not realise that they can ask for social care support. Social care has, in these circumstances, a dual prevention role. By intervening, social care also prevents family members, friends, flatmates and others from placing themselves in physical jeopardy or at risk of mental distress by trying to support someone for whom more formal social care support is needed and preferred.

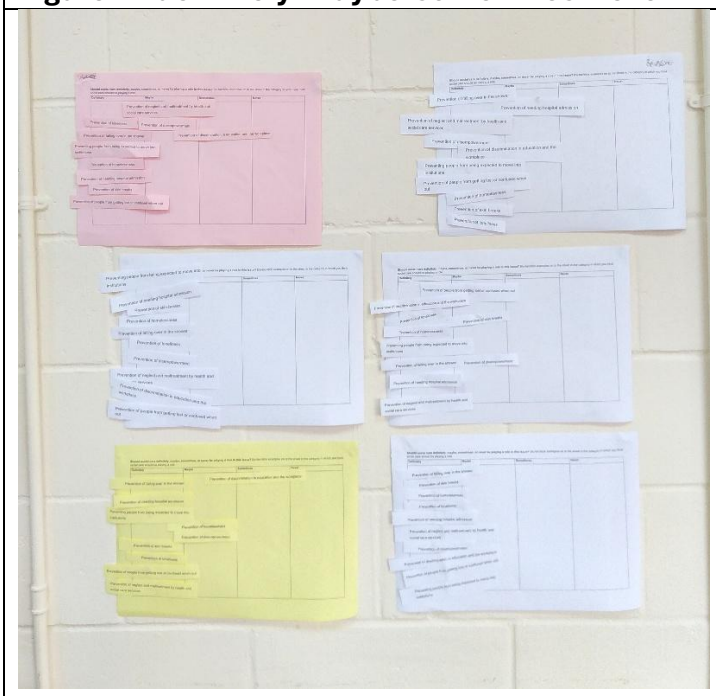
This exercise demonstrated the importance of Primary prevention, and of social care eliciting 'voice' from disabled people to be able to do proactive prevention. It reinforced that disabled people and DPOs can and should be involved with influencing social care prevention policy and practice.

(ii) Exercise 2 - definitely/maybe/sometimes/never

This exercise asked participants to individually consider whether social care should definitely, maybe, sometimes, or never be playing a role in preventing a range of issues. Each participant was given a proforma sheet and ten examples of common themes on which the GDA Community Navigator worked (see Brunner, McAloon, Scobie, and Burke, 2024 pp.14-15). They were asked to stick the examples on to the sheet in the column in which they felt social care should be playing a role. The ten examples were as below, ranging from health-related issues to housing to independent living activities:

1. Prevention of needing hospital admission.
2. Prevention of loneliness.
3. Prevention of homelessness.
4. Prevention of skin breaks.
5. Prevention of falling over in the shower.
6. Prevention of neglect and maltreatment by health and social care services.
7. Prevention of disempowerment.
8. Prevention of discrimination in education and the workplace.
9. Preventing people from being expected to move into institutions.
10. Preventing people from getting lost or confused when out.

Figure 2 - definitely/maybe/sometimes/never



Responses by the six participants are shown in Figure 2. 'Definitely' was the column on the left of the sheet, 'Never' was the column on the right. Responses are strongly skewed to the left, with almost every example under 'definitely'. So, in the view of this sample of disabled people (some receiving, and some needing social care), social care should definitely be playing a preventative role in almost all ten issues.

Prevention of discrimination in education and the workplace was classed as maybe/sometimes, rather than definitely by three participants. In discussion, they explained that it depended on whether the person had good support from their college or their employer; however, social care may still have a role.

Prevention of disempowerment was 'maybe' rather than definitely for three participants. In discussion, one explained that it was about the need for social care to be funding other organisations (Foundational prevention) to provide independent empowerment support - information, advice, advocacy, capacity building etc. They had experienced this with GDA:

> … they should be paying for an independent service to provide that because again, it creates a power imbalance. I was able to fight for things like SDS and have the ability to do that because of the education I got from GDA. If [GDA] hadn't been there, I wouldn't have had the empowerment to do that. So they should be providing another organisation to do that.

This indicates that to prevent lack of 'voice' for people using or needing social care, social care should be funding DPOs, advocacy services and other arms-length organisations, to avert conflicts of interest. This would add to Foundational prevention and enable prevention to be delivered better, as voice would be more clearly heard by social care. However, social care services should in themselves also be preventing disempowerment, through dissemination of information, the way in which they organise assessment and eligibility criteria, and the way in which support is put in place.

The exercise drew out examples of social care doing Primary and Foundational prevention:

> … the social worker came out to visit me for about an hour and a half. So it was quite a detailed conversation. And out of that, she had suggested a befriending group, but she got in touch with them to call me. And she also … got in touch with the local MS group who then came to me to ask what I needed and they sent somebody out twice a week and somebody out to do regular massages. So that suggests that it can work.

Sharing of examples and transparent monitoring and reporting is needed across local authorities to maximise learning from best practice, and to support proactive prevention to happen consistently across Scotland.

People considered how social care can better enable people to access support in the Foundational and Primary categories, and support peoples' needs before they become reactive (Secondary/Tertiary). This is what SDS Standard 2 says that HSCPs should be doing (*'where everyone is welcome to have a conversation about what matters to them'*). Participants gave suggestions:

> *'We could have done that if you had asked'*, but they didn't tell you it's okay to ask. It's okay for your neighbour to ask. It's okay for the women that you meet when you go shopping to ask. They're not advertising that these facilities are available to us, but we have to ask.
>
> I don't always think the government communicate very well what is available.
>
> There's a stigma applied to it, in a way, and it is a horrible thing, isn't it? Oh, *'you need'*, no, I don't need, it's a service that should be given. It's not a need. It should be supplied, rather than begged.

This suggests that to deliver prevention in the Primary and Foundational categories, social care needs to be far more porous, open and non-stigmatised. Social care also needs wider social policy to support it to be more preventative, as a participant noted in relation to social security: *'… they're trying to better life of people with the disabled people, but they're still cutting all the benefit around. So I'm not sure that it's gonna help in any way.'*

Participants were asked *'What would be the big change if we could reinvent social care that would make it more preventative?'* There were many suggestions:

> More flexible.
>
> Listen to disabled people.
>
> Like a kinda drop-in centre.

> … for it to exist like a school exists where people know that it's part of life to go through this. It's like a Citizen Advice … everyone knows they can go… it's active. Maybe community centres, like something that's embedded in people's lives.
>
> Like a one stop shop… Could it be as simple as changing the name? 'A Path to Freedom' or something, you know, something positive …
>
> … it has to have a name that everybody feels they can just walk in, whatever need they've got. There are people there who have an association with the different departments, figure out what you need from what you're saying and deal with it, rather than feeling like you're going to a social security office or a social work office. Somewhere you can go in … with no needs at all.
>
> There needs to be a cultural change. There's this cultural belief … of being a drain on resources when reality, if there was early help from prevention, it wouldn't be seen as much of drain resources 'cause there wouldn't be as much support needed, 'cause you wouldn't hit the crisis point if support was in place first.

One participant summed up the overall benefit of proactive prevention for people needing social care:

> … investing in people reaps rewards, doesn't it? If you're getting looked after, your mental health's good, your physical health's better, you're less demanding perhaps on other services, you're able to go out and pass on your good strength, your good positive vibes. So it's a win-win situation.

These exploratory workshops used facilitated exercises to enable voice by disabled people using and needing social care about their views and experiences of prevention in social care. The workshops were very small and so limited in generalisability. However, the findings illuminate several themes. Participants were clear that social care should 'definitely' play a role in prevention of a broad range of disabled peoples' needs, including supporting independent living activities. Social care should be enabling 'voice', both directly and by supporting DPOs, which would enable more accurate identification of needs. Supporting Foundational organisations also would underpin proactivity in prevention. Reinforcing this is a need for social care and allied services to become more porous and non-stigmatised, and genuinely a place where *'everyone is welcome to have a conversation about what matters to them'* (SDS Standard 2).

4. Conclusion

'... you wouldn't hit the crisis point if support was in place first...'

This *Future Visions for Social Care* research report has innovated methods to gather and synthesise evidence on prevention from disabled people using and needing social care. The workshops were very small, and the findings do not claim to be representative. The study has not had capacity to conduct a systematic review of previous literature. Instead, the work has generated insights on social care prevention for policy, practice and DPOs in Scotland, using methods that future research can adapt more systematically.

It is social care-related services' job to 'do' prevention – including supporting Foundational prevention. The work of the GDA Community Navigator supports disabled people, often those most marginalised, whose voice has not been heard and for whom prevention has not happened. But their work only exists because services have not successfully prevented social care-related needs from arising, in part as they have not successfully enabled and responded to 'voice'. The eight CN cases (Appendix 1) indicate the prospective service costs averted due to the CN's interventions.

The report indicates the benefits that focusing on proactive prevention or *'early help'* in social care, working at the Foundational and Primary levels, could have for disabled people and services alike. However, there is a contrast between the policy expectation of what social care-related services should be doing in terms of prevention, and what people using social care experience, which can feel like the opposite of prevention. Preventing lack of voice is the core underpinning principle to enable services to 'do prevention better' across all four prevention categories. Voice to enable prevention needs to be supercharged by services directly, and by those services funding DPOs and related organisations working in the Foundational prevention category. Arms-length advocacy and self-organised groups facilitate collective voice, enabling social care to more accurately understand disabled peoples' prevention needs.

Much more can be done by HSCPs, IJBs and social care-related services to consistently deliver *'early help'*. Workshop participants needing or receiving social care proposed ideas for how social care can make itself more 'open door' and porous, which would increase the likelihood of prevention practice successfully aligning with prevention policy (Scottish Government, 2025a, 2025b). A listen-advocate-check model, as used by the GDA Community Navigator, may have potential for securing and acting on 'voice'. Prevention also means social care-related services joining up much more effectively; effective prevention in social care is not only the job of social care.

The two workshops show that, using facilitated exercises, disabled peoples' voices can be brought into conceptual and practical thinking about improving social care prevention. This report has therefore prevented lack of voice and empowerment at

policy level. It has also identified that further gaps exist in research on prevention in social care, including:

- Systematic review of literature on disabled peoples' voice in prevention in social care policy and practice.
- Policymakers engaging with disabled people about the four prevention categories and how these can be implemented better.
- Identifying best practice at Primary and Foundational levels of prevention in social care in Scotland.
- What Scotland can learn from other nations about prevention in social care.

This innovative *Future Visions for Social Care* research project has synthesised evidence to support social care-related services in Scotland to re-animate the meaning of prevention as a mode of empowerment and inclusion, and to be able to activate prevention more proactively.

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Appendix 1 – Eight Community Navigator prevention cases

(i) Prevention of multiple health risks through replacement of a broken hoist.

This case encompasses Tertiary (minimising negative consequences) and Secondary (preventing other needs from developing) categories of prevention.

M is a wheelchair user in their 20s who requires to be hoisted in and out of bed and chair.

M called GDA to say they had contacted the social work team to report their hoist was inoperable, that they had called the manufacturer to ask for a repair and been told the hoist was obsolete and no spare parts were available. As such, M needed a new hoist. Social work voiced it was not their responsibility and that M would have to buy one to replace it. M does not have the money for this and is extremely worried.

Because M's paid carers could not assist without a hoist, this meant that M's housemate was lifting them, manually, in and out of bed/chair, which is very risky for both. If M could not get out of bed, they cannot go to work. M is worried about being hurt because of the risks involved in their friend lifting them; the friend being hurt doing the lifting; and their employer becoming annoyed because of failure to attend work in person.

The CN contacted occupational therapy, to ask why they told M they would have to purchase a new hoist for themselves. It was agreed that someone would visit to assess the situation. Later that day, the CN had a call from the district nurse to say they were going to order a new hoist, and that M would not have to pay.

The hoist was delivered the next week.

The initial response by social work that M would need to pay for their own replacement hoist is a response that is the opposite of prevention. Had M not contacted the CN for advice and support, the initial social work decision would have placed M, and M's friend, at continued risk.

The intervention by the CN has prevented lack of 'voice' for M. It has also prevented the below, each of which also holds prospective service costs:

- M from not being able to be being properly assisted by trained carers, thereby avoiding injury and potential hospital admission.
- Potential physical injury to the housemate.
- M from not being able to be at work, risking their continued employment.
- The situation from deteriorating affecting M's mental health and wellbeing.

(ii) Preventing a persecuted disabled person living in a property with an inaccessible toilet from having to continue in the same situation.

This case encompasses Tertiary (minimising negative consequences), secondary (preventing other needs from developing) and Primary (trying to stop problems from occurring) prevention.

N is an increasingly disabled man with a rare syndrome and learning difficulties. He lives in a two-bedroom ground floor flat, but cannot access his bathroom. He has to use a commode in his bedroom when he needs the toilet, and gets a body wash in bed. However, he is physically able to get out of bed; these happen because he cannot access his bathroom, and his house is not suitable for any adaptations. His Occupational Therapist recommended a house move and supported this with a report.

Despite this, N's housing provider say he is on a list with many people worse off than he is, so he never seems to get anywhere. Can you imagine not being able to use a toilet or have a shower in your own home for over a year? N's O/T had contacted the housing provider to impress the importance of the situation, but to no avail.

N is also a victim of neighbourhood bullying and abusive behaviour. He has to keep his bedroom curtains closed. He says local kids look in his window and make fun of him; he is ashamed of his situation and doesn't want anyone to know. He reports that when he goes out in his wheelchair, kids run their bikes into him and call him names. N has reported these matters to the police. He says they said they could not do anything because of the ages of the children. The CN offered to contact the Children's Reporter, but N said that it would have ramifications, so did not give permission.

The CN is in regular contact with the housing provider but all they say is that it's a 'bidding system'. This means that people express an interest in a property which has become available, their need is measured against the needs of others, and the person with the highest need will be successful.

The CN has asked for the support of "HOOPS" (housing options for older people) and Glasgow Centre for Inclusive Living, to see if they can help. It seems homelessness takes priority over N's situation. However, if N was to get a suitable move, he would free a two-bedroom property for a homeless family and get a home suitable for his needs.

The CN has prevented lack of 'voice' for N. Action on the issues identified would prevent the below, each of which also holds prospective service costs:

- N from being harassed.
- N from continuing to live in unsanitary conditions.
- Further distress and anxiety and erosion of mental health and wellbeing.
- Homelessness for another family.

(iii) Prevention of sepsis, pain and further limited mobility.

This case encompasses Tertiary (minimising negative consequences) and some Secondary (preventing other needs from developing) prevention.

T contacted GDA in June 2024 to ask for help to get social care. T is in her 50s, has been a disabled person for her whole life, is a wheelchair user and has had persistent problems with pressure sore areas. She now has further skin issues and requires assistance from social care to apply creams. She did not know how to go about this due to a previous experience of being rebuffed by social work when asking for support. T is an independent person who has pushed herself to manage as best she can. The prevention care she needs now is essential to keep her safe from infections such as sepsis through skin breaks.

The CN supported T to apply online for personal care. The HSCP contacted T the next day for further discussion and assessment. T received care within a week. T now receives visits, three times per week to support her to shower and to apply topical treatments to her skin. She would like an assessment for SDS, but as yet this hasn't happened.

If T had continued without support to apply the topical medication required to maintain skin integrity, there would have been potential for: visits from GPs, antibiotic prescriptions, a more intense level of home support on a daily basis, and a plausible hospital admission.

The CN has prevented lack of 'voice' for T. Their intervention has also prevented the below consequences, saving prospective service costs:

- T becoming ill through skin integrity problems.
- A potential hospital admission due to sepsis.
- Further anxiety and erosion of mental health and wellbeing.

(iv) Seeking to prevent lack of post-hospital discharge social care support.

This case encompasses Tertiary (minimising negative consequences) and Secondary (preventing other needs from developing) categories of prevention.

B is a woman in her 90s, living with mobility restrictions and breathing problems. She has been a very independent and capable person, but is now finding life more difficult. Sometimes her legs are giving way, and she requires some support to carry out personal hygiene and to dress. Below are contemporaneous notes made by the GDA Community Navigator (CN) that describe two hospitalisations and two attempts by the CN to enable post-discharge social care support at home.

Hospitalisation 1

17th Jan 23. B reports she has not received care post-discharge from Queen Elizabeth University Hospital (QEUH) two weeks ago. This is despite being told a package was organized to support her at home. The CN, with permission from B, contacted the hospital discharge team, who said they had not received a referral for B from QEUH. The CN queried this and after discussion it transpired that B's care package had been requested but remained unconfirmed. The discharge co-ordinator is now trying to organize the requested two visits per day for B.

19th Jan 23. The CN called B, who reports that no-one has been in touch about her care package. The CN contacted the hospital discharge team again. They do not have availability of care to offer her at this time. They agreed to put B on a waiting list.

Hospitalisation 2

19th Sept 23. B has been in hospital again, for several weeks. She has discharged herself because she was told she would be moved to a care of the elderly unit. B's stay had been longer than it should have been because of lack of social care. Her Consultant deemed it essential that B be supported on discharge, due to her decreasing ability to manage activities of daily living. A person came to speak with B about moving (query hospital social worker?). He told B they needed her bed and as there was no care at home available, she would be moved to a care of the elderly unit. B was afraid of this, she felt she was going to be put in "an old folks home" and be left there due to lack of homecare services. She told the hospital she would return home without care as she did not want to move to the alternative care facility.

The CN called social work to enquire about B's case. They reported that B had told the hospital social worker she did not need care and was going home. The CN stated someone opting to return home instead of being moved to a care of the elderly unit was quite different from saying they did not need support. The CN added that it was unfair to remove B from the homecare list because of the way someone had recorded her option to go home. The call handler agreed that B should be on the list as priority.

26th Sept 23. B is at home and still has no package of support. The CN contacted social work who say they have nothing to offer B at this time.

2nd Oct 23. B still has no support, The CN contacted social work again, to be told again that B is on a priority list but currently there is no support available.

6th Oct 23. B remains on a priority list with no sign of home support.

A period of no reply from her number.

17th Nov 23. B's son answers the phone. His mother is just home from another hospital stay, having been in hospital since mid-October. She fell and broke her hip attempting to have a shower. She is having a sleep just now. B's son says her health is deteriorating.

21st Nov 23. B is back in hospital with breathing difficulties.

No reply from further calls.

The interventions by the CN enabled voice for B. However, the CN was not able to sufficiently influence the preventative actions needed for B. Had they been successful, re-hospitalisation may have been prevented and those additional service costs averted.

(v) Prevention of a person with learning disabilities becoming homeless and at risk.

This case encompasses Tertiary (minimising negative consequences) and Secondary prevention (preventing other needs from developing).

E is a woman in her 40's with learning difficulties who has always lived with her parents. Her parents are elderly and in poor health, and E's sister and brother-in-law are unable to care for her due to their own commitments.

E left home after a family dispute and was accommodated in a homeless hotel. She found herself in an unfamiliar area with people attempting to get money and belongings from her. She has no care or supervision and no knowledge of the area she has been housed in.

Her sister and brother-in-law provided her with a pre-loaded cash card so they could ensure she had money, and monitor how she was using it. On watching the cash card, it became evident that E was out during the night at local shops.

E started to call GDA in distress, saying she was afraid in the facility she was in. The family also contacted GDA to see if we could support E in any way, as they were fearful of her level of vulnerability. They had already contacted social work who appeared to be "uninterested".

The CN contacted social work to raise concerns about E and her situation, stating that E was an extremely vulnerable person with learning difficulties, who has no experience of looking after herself. The CN mentioned that E was out during the night, and was unable to manage money properly. The CN said that if social work could not look at this again, they would raise an Adult Protection concern. The CN was transferred to a team leader, who agreed the situation was far from ideal. They discussed the family dispute and E's desire to live independently of her parents. The CN asked whether, if E returned home, social work would support them to get a planned move to appropriate accommodation in an area local to her family. They agreed to this.

The CN returned to E and talked her through the homelessness policies, so that she had a deeper understanding of her situation i.e. she could be placed anywhere in the city and would not have any choices. Asking E if she felt safe to return home, she said she was safe but would like her own place now. The CN and E discussed the benefits of a planned move, the fact that she would have choice, and that suitable support would be in place. They agreed that E would consider this overnight.

E returned home the next day with social work supporting a full assessment of needs with a plan to move her to an appropriate supported tenancy when possible.

The work of the CN has prevented lack of 'voice' for E. It has also prevented the below, each of which holds prospective service costs:

- The possibility of E being a victim of exploitation or other foreseeable consequences.
- E being moved to another unfamiliar place without support.
- The potential for crisis services becoming involved.
- Care services having to be involved to ensure her safety during the stay in homeless accommodation.
- Further negative potential impacts on the mental health and wellbeing of E and other family members.

(vi) Preventing a bullied disabled child from being excluded by the education system, and preventing their parent from illiteracy.

This case is Secondary prevention (preventing other needs from developing) for C, and Foundational prevention (supporting partners that nurture strong communities and relationships) for D.

C is a teenage girl with autism, who attends a mainstream school. At school, she was the victim of bullying, culminating in a serious assault. She did not want to return to the school, but wanted to continue in education in order to get to college.

Her aunt, a GDA member, advised C's mother, D, that the CN could help as the young person involved was a disabled person. D contacted GDA to ask for help. D reported that the school seemed to be uninterested in providing any solution for C, simply saying the child who assaulted her would not be in school.

The CN called the school to seek a mutually acceptable solution. The school alluded to having emailed and written to D and to receiving no response. D's take on the matter was that she was waiting for a call from the school, which never came.

The CN managed to broker part-time education with support for C, on days when the perpetrator would be excluded from school. This was acceptable to C and her mother. C was able to return to school with appropriate support for her autism, and be protected from harm.

During the case, the CN found out that D could not read or write, this was why she had not responded to written contact. D told the CN she was embarrassed by this and did not want anyone to know. The CN reassured D that this was not a cause for shame, nor was it unusual. They discussed adult learning for D; she was keen to take part. The CN referred D to adult literacy classes, which D says has increased her ability and confidence. This has boosted her ability to take part in her community, and has the potential to increase her opportunity for employment.

This CN intervention has prevented lack of 'voice' for C and her mother. It has prevented some issues, saving prospective service costs, and expanded the potentials of the family, which may reduce future service costs:

- Prevented a disabled child being marginalised from the education system.
- Meant that C has the chance to proceed onwards to college and a working life ahead, preventing reduced life chances.
- Prevented C's mother, D, from being unable to read or write for life, with all the reduced opportunities that can result.
- By working in the Foundational sphere of educational inclusion and adult literacy, the CN has potentially reduced the chances of social care being involved with the family in future.

(vii) Prevention of homelessness, drug relapse, criminal justice use, and the need for social work and social care intervention and support.

This case is Tertiary prevention (minimising negative consequences) and some Secondary prevention (preventing other needs from developing).

K and their partner are in their 30's. They have two teenage children with autism and addiction issues. K experiences physical and mental health issues; she relies on the support of her partner for the activities of daily living. K and her partner are also in recovery from addiction; her partner is on probation for a criminal charge. Her partner is connected to the criminal justice system, and the Community Addictions Team (CAT).

The family have been in temporary accommodation and were recently offered a permanent home. They were delighted and began to work on the tenancy getting it ready to move in. An ex associate who lived upstairs confronted K's partner a couple of days after commencing work in the tenancy. They knew immediately that the move was impossible; they would be unable to maintain a peaceful life in recovery with the person in the immediate vicinity.

They approached the housing officer and asked that they be allowed to hand the keys back and be considered for another property, explaining that the previous lifestyle and criminal charges were in association with the neighbour. The housing provider initially refused. K contacted GDA for support.

The GDA Community Navigator ascertained that there was a connection to criminal justice and to the CAT Team; if we pulled them together there would be support for the family. The CN contacted Criminal Justice and explained that K's partner is on probation, in successful recovery so far, but that a previous lifestyle associate lived upstairs. If K's partner could not escape this, the situation was likely to result in a possible relapse and potential custodial sentence. This would mean K could not manage the children, requiring social services support, and home care would need to support her daily living activities. The CN then spoke with the CAT worker to explain the housing problem.

With the support of the other agencies, it was agreed that the family could remain in temporary accommodation until another suitable property could be sourced. A short time later, the family were housed in another permanent tenancy. To date they seem to continue to do well supporting each other and remaining in recovery, without home care, without child services, and without a custodial sentence.

The intervention of the CN has prevented lack of 'voice' for K. It has also helped to prevent the below, saving particularly high prospective service costs:

- Potential homelessness.
- Potential drug relapse.

- Prospective criminal justice use.
- The need for social care support.
- Potential child social work intervention.

(viii) Prevention of risk of a disabled person being hospitalised, being in debt, and committing crime, related to substance addiction.

This case is Tertiary prevention (minimising negative consequences) and some Secondary prevention (preventing other needs from developing).

F is in his 40's and has a syndrome that is increasingly affecting his physical mobility. F also experiences seizures.

F contacted GDA for food and fuel support. The CN noted this was the third time in recent weeks that this had happened. The CN called F and asked if they could have a candid discussion. F had a lot of trust in GDA and the CN as they had worked on issues previously; he said the CN could ask anything.

Knowing that F had a historic issue with substance misuse, the CN asked if he was using again, and whether he had debt. F confirmed these were happening and thanked the CN for being "brave enough" to ask him outright. They then discussed the debt and how to manage it, and whether he wanted to reduce his drug use or become abstinent again. They discussed his disability and health issues alongside this.

The CN advised a plan for debt management, and secured food support, fuel support, and a referral to the local Community Addictions Team (CAT).

F managed to clear his debt and keep it that way with the help of the temporary fuel and food support. The CN advised connection to the CAT team due to F having epilepsy; as sudden cessation of drug use would likely exacerbate fitting, a managed reduction would likely prevent health complications and potential hospital admission. Alongside this, being able to manage the payment of the debt would be likely to prevent F committing any criminal activity and reduce the risk of hopelessness. Through this intervention, F is now on a trajectory to return to total abstinence.

This CN intervention has prevented lack of 'voice' for F. It has also supported social care and related services to prevent risks of hospitalisation, crime, and being in a spiral of debt, with all the prospective service costs involved.