North Ayrshire HSCP

Delivering Social Care Services Within Budget

Group Consultation Response

Introduction and context

This consultation submission has been developed by The Community Brokerage Network (CBN) in response to North Ayrshire Council's consultation on health and social care priorities.

CBN is an independent support organisation funded by the Scottish Government to provide free information, advice and support on Self-Directed Support (SDS). For over 12 years, we have been working across Ayrshire with disabled people, unpaid carers and families, supporting them to understand their rights, navigate social care systems, and explore community-based solutions where formal care is not available or does not meet need.

Over the past year, we have seen a significant escalation in crisis-driven referrals, increased complexity, and growing distress among the people we support. Many individuals are coming to us later in the process, often after care packages have already been reduced, reviews have taken place without adequate explanation, or support has been withdrawn entirely. Unpaid carers are increasingly exhausted, financially stretched, and fearful of further cuts.

Against this backdrop, CBN felt it was essential to create space for people with lived experience to engage meaningfully with this consultation. We therefore convened a facilitated focus group involving disabled people, unpaid carers and family members, many of whom attend in multiple roles, to discuss the consultation, its framing, and its potential implications.

While no specific changes have yet been proposed, the consultation takes place in the context of a stated £17 million shortfall in the health and social care budget. Participants were clear that the system is already failing many people and that any further reductions would have what North Ayrshire's Director herself described as a "catastrophic impact" on those who rely on care and support.

A significant source of anger and confusion expressed during the session was the separation of this consultation from the wider council budget consultation, which ran over a different timeframe. Participants questioned why citizens were not being asked to consider health and social care spending alongside other areas of council expenditure, particularly given

widespread concern about perceived inefficiencies elsewhere within local authority structures.

There was strong feeling that internal processes, commissioning arrangements and senior management costs should be examined and addressed before reductions to frontline support for disabled people and unpaid carers are contemplated. Recent media reporting on senior pay increases only heightened the sense of injustice felt by those attending.

Participants also expressed frustration at being asked to make impossible choices, selecting limited priorities from lists that do not reflect the interconnected nature of people's lives, and at a consultation design that appeared to steer responses rather than genuinely seek views.

This submission captures not only responses to the consultation questions, but the fear, anger and deep concern felt by people who are already living on the edge of sustainability. It reflects a strong desire to be part of the solution, and a plea for decision-makers to fully understand the real-world consequences of the choices ahead.

Q1. Please indicate how you are answering this form:

- **Community group Y**
- NAHSCP staff team or service / Provider N

Q2. Please indicate number of participants involved in this collective response: 51

The views captured in this submission reflect the lived experience of at least 30 unpaid carers and 21 cared-for people. While not all unpaid carers and cared-for people were able to attend the session in person due to caring responsibilities and support constraints, perspectives were shared through family members, representatives, and follow-up feedback. Only one cared-for person was able to attend directly, highlighting the very barriers to participation that many disabled people and carers continue to face.

This response is informed by a facilitated focus group hosted by the Community Brokerage Network (CBN) on Friday 9 January 2026. Participants included disabled people, unpaid carers, family members and individuals with lived experience of Self-Directed Support (SDS). Several attendees also brought professional knowledge through work in the social care or third sector, although all contributions were made in a personal capacity, rooted in lived experience. One unpaid carer who works for the local authority attended strictly in their role as a carer, not in a professional capacity.

The session was recorded with participants' consent to ensure people could speak freely without being constrained by forms or pre-set priorities. Participants were clear that they did

not wish to simply "complete the pack", but to explain why the questions themselves felt unanswerable, and to articulate the real-world consequences of the direction of travel suggested by the consultation.

Questions to be put to the group:

Understanding Needs and Priorities

Q3. What aspects of social care do you feel are most important?

Please read out the following and select up to 4 (highlight or circle answers).

- Choice and control over how care is delivered
- Personal safety support (e.g. supports which keep people safe from harm and reduce risks to health and wellbeing including preventing abuse, neglect and exploitation)
- Practical support (e.g. shopping, transport, housework, food preparation)
- Supports to maximise independence (e.g. personal alarms, telecare, equipment and adaptations)
- Care being free of charge
- Models of shared support including services like day care, community hubs and services, advocacy, carers centres, mental health supports, financial inclusion services
- Personal care (e.g. personal hygiene, toileting and continence care, medication, eating and nutrition)
- **Other (Please state)**

Q4. Please provide any additional comments in the box below

What aspects of social care do you feel are most important?
Participants unanimously rejected the framing of this question, which asks people to select only a limited number of priorities from a list of essential supports. The group felt this approach fundamentally misunderstands disability and care needs. People are not homogenous, and no two support packages look the same.

"It depends entirely on what's wrong with you and what support you need. You can't compare one person's needs with another's."

Participants stressed that all of the listed elements, personal care, safety, choice and control, practical support, independence, community support, and care being free of charge, are interconnected. Removing one destabilises the rest.

"Every disabled person needs an element of all of that. Asking us to pick four is impossible."

The group highlighted that choice and control is not optional, it is the foundation of SDS under the Social Care (Self-directed Support) (Scotland) Act 2013. To ask people whether it is important is, in itself, concerning.

"Why is choice and control even a question? That's the whole point of SDS."

Similarly, safety cannot be separated from other forms of support.

"Every single form of support prevents neglect. You can't pull one bit out and say the rest don't matter."

Q5. Which of these services do you feel are most integral to people's care?

Please read out the following and select up to 5 (highlight or circle answers).

- Personal hygiene (e.g. bathing, showering, hair washing, shaving, brushing teeth)
- Getting dressed (e.g. changing clothes, using prosthetics or other aids)
- Eating and drinking (e.g. help with eating, preparing food and managing special diets)
- Mobility (e.g. help getting in and out of bed, moving around home)
- Continence management (e.g. help with toileting, changing continence laundry, and stoma or catheter care)
- Medication and treatment (e.g. assistance with taking medication (like eye drops), applying creams, and simple dressings.)
- Emotional support (e.g. counseling, psychological support, and help with reminders or behavior management.)
- Housework, making beds, and laundry
- Shopping and running errands
- Transport for appointments or other activities
- Telecare services like community alarms
- Day services

Q6. Please provide any additional comments in the box below:

Participants were clear that this question, as framed, is not realistically answerable and does not reflect how care works in real life.

The list presents essential elements of daily living as if they are discrete, interchangeable services that can be ranked or traded off against one another. For people with disabilities,

long-term conditions, or complex needs, these supports are interdependent. Removing any one of them destabilises the whole package.

"You can't separate these things. They all work together. Take one away and everything else starts to fall apart."

Participants rejected the idea that it is possible or appropriate to select only five items from this list. The support someone requires at any given time depends entirely on their impairment, health, environment, mental wellbeing, and personal circumstances.

"It depends entirely on what's wrong with you and how you function. One person might need help physically, another cognitively, another emotionally, most people need a mix."

Several people highlighted that the way the list is broken down is itself artificial. For example:

- getting dressed cannot be separated from mobility
- eating and drinking cannot be separated from food preparation or shopping
- continence care cannot be separated from laundry or emotional support
- medication support cannot be separated from prompting, reassurance, and observation

"If you help someone shower but leave them in a dirty bed because laundry isn't 'essential', what are you actually achieving?"

Emotional and psychological support was repeatedly raised as being treated as optional or secondary, despite being fundamental to safety, dignity, and wellbeing.

"Try providing continence care or medication without reassurance or communication. You can't do it safely or humanely."

Day services, transport, and community-based support were also described as essential, not discretionary. These supports prevent isolation, protect mental health, and enable carers to sustain their role.

"Take away day services or transport and people become housebound. Then mental health deteriorates, carers burn out, and costs increase."

Participants felt the question risks pitting people against each other, implying that some needs are more legitimate than others, when in reality all listed supports are core components of care depending on the individual.

"This feels like asking which parts of your life you can live without."

The group emphasised that care must be person-centred, as required under Self-Directed Support legislation and guidance. Needs should be assessed holistically, not broken down into isolated tasks and ranked for removal.

"People aren't a list of tasks. They're human beings."

In summary, participants did not select five items because:

- all listed services may be integral depending on the person
- separating them creates false distinctions
- prioritising some inevitably leads to harm, crisis, and greater cost later

The overwhelming message from the group was that this question does not capture lived experience and risks being used to justify reductions that will have serious and foreseeable consequences.

Q7. How do you feel about prioritising personal care over non-personal care when resources are limited?

Personal care includes intimate daily living supports - personal hygiene, toileting and continence care, medication, eating and nutrition

Non-Personal Care includes - shopping, transport, cleaning, laundry and housework, food preparation, social activities

Please highlight or circle the groups response below:

- Strongly agree
- Agree
- Neutral
- Disagree
- **Strongly disagree**

Q8. Please provide any additional comments in the box below

Participants strongly disagreed with the idea that "personal care" can be meaningfully separated from so-called "non-personal" support.

They explained that tasks such as shopping, cleaning, transport, laundry, emotional reassurance, and prompting are often what enable personal care to happen safely, consistently, and with dignity.

"If someone doesn't get help with shopping, how do they eat? If they're left in a dirty bed, what happens next? Hospital."

The group described this framing as false, reductive, and dangerous, particularly for people with learning disabilities, autism, mental health needs or fluctuating conditions.

"All care is personal when you're disabled."

Participants stressed that non-personal support is often the preventative layer that keeps people well, avoids crisis, and reduces long-term cost. Removing it was seen as undermining the purpose of social care entirely.

There was strong concern that drawing this distinction would disproportionately impact people whose needs are less visible, reinforcing inequality and increasing safeguarding risk.

In summary, participants felt that separating personal and non-personal care creates artificial hierarchies of need, ignores lived experience, and risks increasing harm rather than reducing cost.

Eligibility and Access

Q9. Do you know that there is eligibility criteria for care?

Please read out the following: *Eligibility criteria are the individual circumstances that are met where an individual can access formal social care supports*

Following discussion, please highlight or circle either:

- Yes
- **No**

Q10. Please provide any additional comments in the box below

Participants expressed deep concern about a lack of transparency around eligibility criteria.

Some attendees, including those with long-standing involvement in the system, were unaware of the specific thresholds applied in North Ayrshire. Others noted that even frontline staff appear unclear.

"We've never been given the eligibility criteria. Not even internally."

The group felt strongly that people should not need to understand scoring systems, legislation, or policy language to access support.

"A parent of a disabled child should not need to quote legislation to get help."

This lack of clarity was seen as actively disadvantaging people who are less confident, less articulate, or without advocacy, precisely those most at risk of unmet need.

Q11. If the group answered yes above, how clear and accessible did they find the current eligibility criteria for care?

Please provide any additional comments or examples in the box below

Participants who were aware that eligibility criteria exist did not find them clear or accessible.

Several people stated that they had never been provided with written eligibility criteria, nor had thresholds or scoring processes been explained during assessment or review.

"You're assessed, but you're never told what the rules actually are."

Where information was provided, it was often described as inconsistent, overly technical, or dependent on the individual worker's interpretation. Participants felt this lack of clarity made it difficult to understand decisions, prepare for assessments, or challenge outcomes.

The group was clear that eligibility criteria should be transparent, consistently applied, and explained in plain language, and that people should not need specialist knowledge or advocacy to understand how decisions are made.

Q12. Out of the following approaches, which one should be prioritised to ensure fairness and sustainability of eligibility criteria?

Please highlight or circle one:

- Apply consistent thresholds across all services
- **Consider individual circumstances case-by-case**
- Focus on those with highest or greatest need

Q13. Please provide any additional comments in the box below

Participants overwhelmingly supported case-by-case decision-making, grounded in individual circumstances, lived experience, and meaningful conversation.

There was strong and consistent rejection of blanket eligibility thresholds, standardised comparisons, or approaches that attempt to rank need across different impairments or life situations.

"How do you compare a physical impairment to a learning disability? It's a loser's game."

The group was clear that fairness does not mean sameness. Treating people "equally" by applying rigid thresholds or generic criteria ignores the reality that disabled people experience very different barriers, risks, and support needs.

Participants repeatedly returned to the principles of the Independent Living movement, which fought to move people away from institutionalised care and towards lives rooted in community, autonomy, dignity, and participation. There was deep anxiety that current proposals represent a reversal of that progress.

"We've spent decades trying to get people out of institutions. This feels like dragging us back there."

Participants expressed fear that narrowing eligibility and prioritising only "critical" needs would reduce disabled people's lives to mere survival, being washed, fed, and kept alive, rather than enabling them to live full lives as citizens.

"They're not talking about living. They're talking about existing."

This was seen as fundamentally incompatible with the Social Care (Self-directed Support) (Scotland) Act 2013, which is explicitly underpinned by principles of:

- choice and control
- dignity and respect
- participation in community life
- involvement in decisions affecting one's life

Participants warned that blanket approaches risk undermining SDS in its entirety, turning it from a rights-based framework into a rationing exercise driven by cost rather than need.

"You can't claim to support Self-Directed Support while stripping away everything that makes life worth living."

Several carers spoke emotionally about the message such approaches send — that disabled people's lives are valued less than those of non-disabled people, and that they should accept isolation as the price of needing support.

"It's basically saying our lives aren't worth the same."

The removal of support that enables people to go out, socialise, work, attend activities, or maintain relationships was described as discriminatory, breaching the spirit, and potentially the letter, of human rights legislation.

Participants highlighted that the UN Convention on the Rights of Persons with Disabilities (UNCRPD), to which Scotland is committed, affirms disabled people's right to:

- live independently
- be included in the community
- have equal opportunities to participate in social, cultural, and economic life

The group felt that proposals which confine people to their homes, limit support to personal care only, or push individuals toward residential care directly contradict these obligations.

One carer described the direction of travel in stark terms:

"This is edging towards something much darker. It's like saying some lives are worth investing in and some aren't. It feels like eugenics."

While this language reflects the depth of fear and distress in the room, it underscores how profoundly threatening these proposals feel to families who have spent years fighting for dignity, safety, and inclusion.

Participants also emphasised that case-by-case decision-making is not only more humane but more sustainable. Early, flexible, individualised support prevents crisis, protects unpaid carers, and avoids far greater costs later.

"Rigid thresholds don't save money. They just delay the bill — and make it bigger."

In summary, the group strongly believes that:

- eligibility decisions must be individual, not formulaic
- sustainability cannot be achieved by withdrawing rights
- fairness must be rooted in equity, dignity, and human rights

Any move away from person-centred decision-making risks undoing decades of progress, increasing institutionalisation, and entrenching discrimination against disabled people and their families.

Q14. Thresholds for accessing social care are set locally to establish the point at which a local authority will provide an individual with care. What concerns might arise if thresholds for accessing care were changed in the future?

Thresholds for care is a legal and professional standard that determines a level of harm or risk an individual is experiencing which must be met before a local authority will intervene with care.

Please provide any comments in the box below

Participants were unequivocal about the likely consequences of raising eligibility thresholds, particularly any move to a "critical needs only" model.

This was not viewed as a neutral financial measure, but as a decision that would inevitably escalate risk, shift pressure onto unpaid carers and other public services, and result in significantly higher costs over time.

"You're not removing need. You're just delaying it until it explodes."

Participants consistently described how small amounts of support, provided earlier and flexibly, often prevent crisis. Removing access to support at the "substantial" level was seen as dismantling this preventative function entirely.

"Tiny bits of support keep people going. Take that away and everything collapses."

The group identified clear and foreseeable consequences of raised thresholds, including:

- escalation from manageable situations into crisis
- increased safeguarding concerns
- avoidable hospital admissions
- breakdown of informal care arrangements
- greater reliance on emergency and residential services

"People will die. Those who don't will need far more care later."

There was strong consensus that a critical-only threshold would undermine the purpose of Self-Directed Support by shifting the system from prevention and enablement to crisis management.

Participants stressed that this approach is neither sustainable nor efficient, as it ignores well-established evidence that early, person-centred support reduces long-term demand and cost.

"This doesn't save money. It just moves the cost somewhere else."

The group was clear that thresholds should not be used as a blunt rationing tool, and that sustainability must be achieved through early intervention, flexibility, and proportionate responses, not by withdrawing support until situations become unsafe.

Q15. What do you see as the most effective ways to communicate eligibility criteria and decisions?

Following discussion, please highlight or circle all that apply:

- **Clear written guidance**
- **Conversations with care staff**
- **Online tools or explainer videos**
- **Community events or drop-ins**
- **Feedback after any appeals and complaints process**

Q16. Please provide any additional comments in the box below

Participants were clear that no single communication method is sufficient and that effective communication about eligibility and decisions must use all available channels, including:

- clear written guidance
- meaningful, face-to-face conversations
- accessible online tools and explainers
- community-based engagement and events

However, the group stressed that the issue is not simply about communication tools, but about honesty, consistency, and credibility.

Participants described a growing disconnect between what people are told about Self-Directed Support in principle and what they experience in practice.

"You're told one thing on paper, and something completely different happens when you try to access support."

A recurring theme was that frontline staff themselves often do not fully understand SDS legislation, eligibility criteria, or people's rights. Several participants described situations where they were required to educate professionals about the law and national guidance.

"I had to send the social worker the guidance because they didn't know it."

This lack of shared understanding was seen as deeply problematic, particularly as SDS is still actively promoted by local authorities on their websites as a rights-based, choice-led system aligned with Scottish Government policy.

Participants highlighted the growing vacuum between legislation and practice. While SDS principles - choice, control, dignity, and participation - continue to be publicly endorsed, local procedures and internal policies were described as being increasingly out of sync with those principles.

"They still talk about choice and control, but the reality is that choice is disappearing."

Independent support organisations were described as being caught in the middle of this widening gap. Participants noted that tension is growing between social work teams and independent advice providers, with claims that organisations are giving people "incorrect information".

The group strongly rejected this characterisation.

Independent support organisations, including those present in the room, provide information and advice grounded in SDS legislation and statutory guidance developed by the Scottish Government, which also funds these services to support people to understand their rights.

"We're not making this up. We're telling people what the law and guidance actually say."

Participants expressed concern that instead of addressing inconsistencies between policy and practice, local systems appear to be discrediting independent advice because it challenges operational decisions driven by financial pressure.

"It's easier to say the advice is wrong than to admit the system isn't matching the law."

This dynamic was seen as damaging trust, not only between families and professionals, but across the wider system. Participants stressed that independent support should be viewed as a partner and safeguard, not as an obstacle.

"If independent advice is treated as a nuisance, people lose one of the few protections they have."

There was also concern that eligibility criteria and decision-making processes are not being communicated transparently. Several participants stated they had never been given a copy of eligibility criteria, nor had the process for scoring or thresholds been clearly explained.

"You're assessed, but you're never told what the rules actually are."

This lack of transparency was described as leaving people unable to understand, challenge, or prepare for decisions that profoundly affect their lives.

Participants stressed that meaningful communication must include:

- clear explanations of eligibility thresholds and how decisions are made
- honest discussion about limitations and constraints
- consistent messaging across staff, services, and partners
- recognition of independent advice as legitimate and necessary

Without this, participants warned that distrust will continue to grow, conflict will escalate, and people will increasingly experience the system as adversarial rather than supportive.

"Right now, it feels like you have to fight just to be heard."

In summary, participants believe that effective communication about eligibility and decisions requires more than better leaflets or websites. It requires:

- alignment between law, policy, and practice
- staff who are confident and competent in SDS
- respect for independent advice and advocacy
- transparency that enables informed choice and challenge

Without these foundations, communication risks becoming a mechanism for managing expectations, rather than a tool for enabling rights and informed decision-making.

Choice and Cost

Q17. How important is it that people get to choose how their own care is organised and delivered?

Please read out the following: *In Scotland people who are eligible for social care are able to decide how their support is arranged and delivered. People get to select the type of support that best fits their lifestyle, cultural needs, and personal goals and have the ability to decide who provides their care, how and when support is delivered and can manage their own care budget.*

Please highlight or circle the groups response below:

- **Very important**
- Somewhat important
- Neutral
- Not very important
- Not important at all

Q18. Please provide any additional comments in the box below

Participants were unanimous that choice and control over how care is organised and delivered is fundamental, not optional, and sits at the very heart of Scotland's social care system as set out in the Social Care (Self-directed Support) (Scotland) Act 2013.

Choice was not described as a "preference" or a "nice to have", but as essential to:

- dignity
- safety
- wellbeing
- independence
- participation in family and community life

"Choice is the difference between living and just existing."

Participants emphasised that SDS was introduced specifically to move away from rigid, service-led models and towards person-centred support, recognising that disabled people are experts in their own lives.

"People know what works for them. Taking away choice ignores that."

The group expressed deep concern that while the language of choice and control continues to be promoted by local authorities and the Scottish Government, the reality of practice is moving in the opposite direction. Increasing restrictions, capped rates, limited provider options, and refusal to offer flexibility were all cited as examples of choice being eroded in practice.

"They still talk about choice, but it's becoming meaningless."

Several participants highlighted that being able to choose who provides care, when support happens, and how it fits around daily life is often what makes care safe and sustainable, particularly for people with complex needs, trauma histories, or communication differences.

"The wrong person at the wrong time can make everything worse."

Choice was also described as critical to maintaining unpaid carers' ability to cope, particularly where flexible arrangements allow carers to work, rest, or share responsibility.

- Participants stressed that removing or weakening choice would:
- increase distress and anxiety
- undermine trust
- destabilise care arrangements
- increase the likelihood of crisis and breakdown

The group was clear that choice is not a luxury that can be sacrificed in times of financial pressure. It is a core legal and ethical requirement, and any approach that diminishes it risks breaching the principles and intent of SDS legislation and Scotland's human rights commitments.

"If choice goes, SDS goes with it."

Q19. Should there be limitations placed on choice to reduce costs and ensure sustainability of services?

Following discussion, please highlight or circle one option:

- Yes
- **No**
- Unsure

Q20. Please provide any additional comments in the box below

Participants were unequivocal that limiting choice to reduce costs is neither sustainable nor acceptable, and that framing the issue this way creates a false and dangerous narrative.

The group rejected the idea that choice is the cause of financial pressure within social care. Instead, they argued that restricting choice often increases costs by destabilising effective arrangements and forcing people into more expensive or inappropriate forms of support.

"When you take away what works, you create crisis – and crisis costs more."

Participants gave multiple examples where lack of choice has already led to:

- breakdown of Personal Assistant arrangements
- reliance on higher-cost care providers
- hospital admissions
- increased unpaid care
- deterioration in mental and physical health

Choice was repeatedly described as a protective factor, enabling people to design support that works, keeps them safe, and prevents escalation.

"Choice is what keeps things stable."

The group expressed strong concern that limiting choice would disproportionately impact:

- people with complex or fluctuating needs
- those employing Personal Assistants
- people without family advocacy
- unpaid carers already at breaking point

Participants also warned that limiting choice under the guise of "sustainability" risks undermining the entire SDS framework, turning it into a cost-containment exercise rather than a rights-based system.

"That's not Self-Directed Support. That's rationing."

There was particular frustration that choice is often restricted while inefficiencies elsewhere in the system remain unchallenged, including:

- costly internal processes
- repeated reassessments
- delayed decision-making
- inconsistent application of policy

"It's always disabled people who are asked to give things up first."

Participants stressed that true sustainability comes from:

- early intervention
- flexible, individualised support
- trusting people to design what works
- investing in community-based solutions
- not from narrowing options and forcing people into one-size-fits-all models.

"You don't save money by stripping people of control. You just move the cost down the line."

In summary, the group strongly believes that:

- choice must be protected, not restricted
- sustainability cannot be achieved by removing rights
- limiting choice will increase long-term cost and harm

Any approach that places cost control above choice risks reversing decades of progress, undermining SDS legislation, and sending a clear message that disabled people's autonomy is negotiable.

"If sustainability means taking away our rights, then something is very wrong."

Q21. In times of limited resources, does the group feel that cost limits should be placed on individual care packages?

Please highlight or circle the groups response below:

- Strongly agree
- Agree
- Neutral
- Disagree
- **Strongly disagree**

Q22. Please provide any additional comments in the box below

Participants were unequivocal in their opposition to placing cost limits on individual care packages, particularly during periods of financial pressure. The group viewed cost limits as a blunt, arbitrary mechanism that bears no relationship to individual need and fundamentally undermines the principles of Self-Directed Support.

"Need doesn't stop at an arbitrary figure."

Participants stressed that care needs are determined by impairment, health, risk, and circumstance — not by budget ceilings. Applying cost limits was described as incompatible with the Social Care (Self-directed Support) (Scotland) Act 2013, which requires assessments to be based on individual outcomes and needs, not predetermined financial caps.

"You assess need first. You don't decide the price and work backwards."

The group highlighted that cost limits inevitably result in hidden rationing, where people with higher or more complex needs are penalised for circumstances entirely beyond their control.

"It's basically punishing people for being more disabled."

Participants expressed serious concern that cost limits would disproportionately affect people with:

- complex or multiple impairments
- high support needs
- communication difficulties
- limited family advocacy

"Those who need the most will lose the most."

There was also strong concern that cost limits would push people towards institutional or residential care, even where community-based support is safer, more appropriate, and often more cost-effective.

"If you can't live within the limit, they start talking about residential. That's not a choice."

This was seen as a direct contradiction of the Independent Living movement, which sought to move people out of institutions and into communities, and of Scotland's commitments under the UN Convention on the Rights of Persons with Disabilities.

Participants emphasised that cost limits do not create sustainability; instead, they:

- destabilise effective support arrangements
- increase crisis interventions
- raise long-term costs to the NHS and other services

- shift pressure onto unpaid carers

"You save money on paper and spend more in reality."

Several carers described the fear and anxiety caused by discussions of cost limits, particularly when framed alongside reassessment or review processes.

"It feels like a threat — stay quiet or you'll lose everything."

The group also highlighted the lack of transparency around how cost limits would be set, applied, or reviewed, and how they would account for market realities such as workforce shortages and rising care costs.

"The system creates the cost pressures, then blames individuals for being 'too expensive'."

Participants were clear that sustainability must be achieved through:

- early intervention
- flexible, person-centred support
- investment in the workforce
- addressing systemic inefficiencies
- not by imposing arbitrary financial ceilings on people's lives.

"You don't balance budgets by capping human need."

In summary, the group strongly believes that placing cost limits on individual care packages would:

- undermine SDS legislation
- increase inequality and discrimination
- reverse progress on independent living
- lead to higher long-term costs and harm

and should not be pursued under any circumstances.

Q23. Should people be charged for or contribute to the cost of non-personal care?

Please read out the following: *Currently service users contribute to the cost of Non-Personal Care, these charges are based on an individual's ability to pay after a financial assessment. Non-Personal Care includes - shopping, transport, cleaning, laundry and housework, food preparation, social activities.*

Following discussion, please highlight or circle one option:

- Yes
- **No**
- Unsure

Q24. Please provide any additional comments in the box below

Participants did not take the view that all contributions to non-personal care are inherently inappropriate. However, there was strong agreement that current charging practices are unfair, poorly communicated, and disproportionately impact people with the least ability to pay.

The group was clear that any contribution must be genuinely proportionate to a person's financial circumstances and must fully account for disability-related expenses. Participants were particularly concerned about people whose only income is benefits, who are often asked to contribute despite having no realistic disposable income.

"You can't squeeze money out of people who don't have any."

There was widespread frustration that people are not routinely informed that disability-related expenses can be offset during financial assessments. As a result, individuals who are unaware of this are unfairly penalised.

"Protection shouldn't depend on how well you know the system."

Participants also highlighted cases where the proposed charge for non-personal care exceeded the cost of arranging support directly, particularly through Personal Assistants, which was seen as illogical and actively undermining independence.

The group felt strongly that charging should never push people into poverty, deter them from accessing essential support, or transfer additional burden onto unpaid carers. Without significant reform, current charging practices were viewed as inequitable and unsustainable.

Q25. Should charging policies be designed to protect those on low incomes?

Following discussion, please highlight or circle one option:

- **Yes**
- No
- Unsure

Q26. Please provide any additional comments in the box below

Participants were unequivocal that any charging policy must be explicitly designed to protect people on low incomes, particularly disabled people whose sole income is benefits and who face unavoidable additional costs linked to impairment.

The group stressed that charging policies which fail to do this are inherently regressive and risk deepening poverty, inequality, and social exclusion.

"If the policy doesn't protect people on low incomes, it's not fair – it's punitive."

Participants emphasised that many disabled people live on fixed or very limited incomes and already experience higher day-to-day costs, including:

- increased energy usage
- specialist diets
- transport costs
- additional laundry and household wear
- equipment and personal care items

Charging policies that do not fully and proactively account for these realities were seen as structurally flawed.

"The assessment might say someone can afford it, but real life says they can't."

A key concern raised was that people are not routinely informed about disability-related expenses (DRE) or supported to evidence them during financial assessments. As a result, individuals who are unaware of their rights are disproportionately penalised.

"Protection shouldn't depend on how well you know the system."

Participants felt strongly that protection for those on low incomes should be:

- automatic, not discretionary
- clearly explained and consistently applied
- embedded in policy, not reliant on challenge or appeal

The group also highlighted that charging policies which fail to protect low-income households place indirect pressure on unpaid carers, who are expected to absorb gaps when support becomes unaffordable.

"When people can't pay, the care doesn't disappear – it lands on families."

This was seen as particularly concerning given the well-documented links between unpaid caring, poverty, poor mental health, and withdrawal from employment.

Participants stressed that protecting people on low incomes is not only an equality issue, but a preventative and economic one. Where charges lead to people declining support, reducing usage, or falling into crisis, the cost inevitably reappears elsewhere.

"You don't save money by pushing people into crisis."

There was also concern that inconsistent application of charging policies across services creates confusion and mistrust, with people unable to understand why they are being charged, how amounts are calculated, or what protections exist.

"If you can't explain it clearly, it's not working."

In summary, the group believes that:

- charging policies must protect people on low incomes
- disability-related costs must be fully recognised
- protections should be proactive, transparent, and consistent
- no one should be pushed into poverty as a result of needing support

Without these safeguards, charging policies risk becoming discriminatory in effect, even if not in intention.

Equality and Impact

Q27. How could introducing cost limits or raising care thresholds for care packages affect people who use services?

Please provide comments or examples in the box below

The discussion highlighted profound equality and human rights concerns, particularly regarding the cumulative impact of proposed changes on unpaid carers and the households they support.

Participants were clear that disabled people do not experience the impact of reduced support in isolation. Any reduction in formal care is immediately absorbed by unpaid carers, many of whom are already providing care far beyond what is safe or sustainable.

"When support is cut, it doesn't disappear – it lands on families."

Carers described living in a constant state of exhaustion, often providing care overnight and throughout the day with little or no respite. Many spoke about being up multiple times during the night and then expected to continue caring, manage households, or work the next day.

"You're running on empty all the time. There's nothing left to give."

Employment was a major theme. Several carers shared that they had already reduced their working hours or left employment entirely because support was unreliable or unavailable.

In the current economic climate, participants stressed that most households require two incomes to survive. When carers are forced out of work:

- household income drops sharply
- families are pushed into poverty
- carers lose independence, identity, and future security

"I didn't stop working by choice. I stopped because there was no support."

Participants described the mental health impact of this loss, anxiety, depression, isolation, and a sense of being trapped in the home with no financial autonomy.

"You're stuck in the house, no money, no break. That destroys your mental health."

The group emphasised that unpaid carers are not an unlimited resource, yet current proposals assume they will simply absorb further cuts regardless of their own health or circumstances.

"They act like carers will always step in. But many of us are already broken."

There was strong recognition that these impacts are not evenly distributed. Unpaid care is predominantly provided by women, meaning raised thresholds and reduced support would disproportionately push women out of employment and into poverty.

"This will hit women hardest. That's not an accident – it's how the system is built."

Participants also highlighted the wider equality implications:

- increased social isolation
- reduced participation in community life
- loss of dignity and autonomy
- long-term health deterioration for both carers and disabled people

The group stressed that these outcomes conflict directly with:

- the principles of Self-Directed Support
- Scotland's commitments under the UN Convention on the Rights of Persons with Disabilities
- duties to promote equality, prevent discrimination, and protect family life

"This isn't just about budgets. It's about whose lives are considered worth supporting."

In summary, participants believe that raising eligibility thresholds would:

- deepen inequality
- accelerate poverty
- damage carers' health and wellbeing
- increase long-term public sector costs

and would represent a serious failure to consider the real human impact of these decisions.

Q28. What additional support might be needed for vulnerable people?

Please provide any comments or examples in the box below

Participants challenged the framing of this question, emphasising that people are not inherently vulnerable because they are disabled or require support. Rather, people become vulnerable when appropriate support is removed, delayed, or made inaccessible.

"Disabled people aren't vulnerable by default. They're made vulnerable by the system."

The group was clear that the most effective way to reduce vulnerability is early, consistent, and person-centred support, delivered in line with Self-Directed Support principles. Where small amounts of flexible support are available at the right time, crisis can often be avoided.

"Tiny bits of support keep people going. Take that away and everything collapses."

Participants identified several areas where additional support is urgently needed, particularly for people who are least able to navigate the system or advocate for themselves.

First, there was strong agreement that independent information, advice, and advocacy are essential. Many participants described the system as complex, opaque, and intimidating, with eligibility criteria, charging policies, and SDS options poorly explained or inconsistently applied.

"If you don't know your rights, you don't get support."

Independent support organisations were described as a critical safeguard, particularly for people without family advocates, those with communication barriers, or individuals experiencing mental distress.

Second, participants highlighted the need for earlier involvement of support services, particularly at key transition points such as:

- leaving school
- moving between children's and adult services

- hospital discharge
- onset or progression of illness

Delays or gaps at these points were described as creating avoidable crisis and long-term harm.

"By the time support arrives, it's already too late."

Third, the group stressed the importance of support for unpaid carers, recognising that carers are often the first line of defence against crisis. This includes:

- timely access to respite
- flexible support arrangements
- recognition of carers' health, employment, and wellbeing needs

"If carers collapse, the whole system collapses with them."

Participants also highlighted the need for clearer communication and workforce training, so that frontline staff fully understand SDS legislation, eligibility criteria, and people's rights. Where staff lack confidence or knowledge, people experience inconsistent decisions and misinformation.

"We're having to educate professionals about the law."

There was concern that people who communicate non-verbally, have cognitive impairments, or experience mental health distress are particularly disadvantaged by current processes. Participants stressed the need for:

- accessible communication
- trusted relationships
- time to build understanding
- continuity of staff

Finally, the group emphasised the importance of community-based, preventative support, including peer support, social connection, and practical assistance that helps people remain part of their communities.

"Isolation is one of the biggest risks of all."

In summary, participants believe that additional support for those at risk of vulnerability should focus on:

- preventing crisis rather than responding to it
- empowering people with information and choice
- supporting unpaid carers

- strengthening independent support and advocacy
- ensuring flexibility, consistency, and dignity

Without these supports, vulnerability is not reduced, it is created.

Q29. Any other feedback?

Please provide any comments in the box below

Participants used this section to raise two overarching concerns not fully captured elsewhere:

(1) the unintended workforce and market consequences of current proposals, and

(2) serious concerns about the design and credibility of the consultation process itself.

1. Cost limits, workforce issues and unintended consequences

This discussion focused heavily on Personal Assistants (PAs), workforce sustainability, and financial inconsistency.

Many people using SDS in North Ayrshire employ PAs who work exclusively for one individual, as PAs are not permitted to be self-employed locally. This means PA roles depend on having enough consistent hours to be viable.

Participants warned that reducing support deemed "non-critical" would result in fragmented shifts, short visits, unpaid travel, and insufficient hours.

"No one can survive on that. They'll leave."

This puts people at high risk of losing trusted staff, forcing them toward care providers, at higher cost and with less continuity.

The group described a system already at breaking point, where:

- providers with capacity charge £5–£10 per hour more than the council rate
- people unable to pay the difference are left with no support
- internal care services cost significantly more than the published external rate

"The council pays more for its own staff but expects people on SDS to manage with less."

Participants also raised concerns about Fair Work. While internal staff receive Real Living Wage uplifts immediately, Direct Payments and providers often wait months for equivalent increases.

"You can't promote Fair Work and then underfund the people trying to employ fairly."

There was frustration that creative, cost-effective solutions, such as employing family members who are not guardians, paying higher rates for complex work, or flexible hybrid models, are repeatedly dismissed in favour of suggesting residential care.

"Residential is always used as a threat, but everyone knows it costs more."

This, combined with inconsistent figures around residential costs, fuelled distrust.

"The figures they are promoting don't stack up. It feels like the outcome is already decided."

2. Process concerns and trust in the consultation

Across the group there was a strong sense that the consultation process itself is flawed.

Concerns included:

- a separate and shorter consultation timeline from the main council budget
- running over the Christmas period
- questions that force people to choose from impossible options
- initial inability to complete the survey without selecting required priorities

Participants felt this shaped responses to justify pre-planned decisions, rather than genuinely gathering views.

"It feels designed to give them the answers they want."

Feedback also raised additional concern that:

- the consultation has not been well promoted internally
- frontline care-at-home staff have not been actively encouraged to participate

This is seen as a missed opportunity to hear from those closest to the impact of decisions.

Final comments in the words of an unpaid carer:

One carer who had hoped to attend the focus group was unable to do so because the support she relies on did not turn up on the day. After reading the draft consultation response, she shared the following reflections, which we believe strongly capture the reality facing many families:

"The survey itself was written with a 'catch all', episodic, medical model narrative. It forces people to unwillingly 'agree' to cuts that directly impact their ability to live and that erode human rights.

North Ayrshire has become a place to live in fear if you have a disability yourself, or if you care for someone who does. The fundamentals of health and social care, and especially Self-Directed Support, are being systematically eroded.

The discrimination in wages alone between Personal Assistants and local authority social care staff is one example of this erosion. To what end? For those of us caring and managing budgets on behalf of the partnership, we are cheap at the price.

This collective response genuinely encapsulates everything I am concerned about."

This contribution reflects not only the content of the consultation, but also the lived reality that many carers experience: being excluded from participation because support systems are already failing.

If further information would be helpful, or if there is an opportunity to discuss the content of this submission in more detail, please do not hesitate to get in touch. I would welcome the chance to explore the issues raised and to contribute constructively to any further dialogue or engagement.

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