

Navigating social care, independent living and human rights

Four Community Navigator cases from
Future Visions for Social Care

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Introduction

A significant feature of the 2022-23 GDA Future Visions project has been the role of the Community Navigator in supporting disabled people in Scotland who are not having their needs served by the social care system. Community Navigator support offers flexible timing, according to individual situations - sometimes rapid intervention, sometimes long-term support. The cases they support are very wide-ranging, from the relatively simple to the highly complex. They include people experiencing breaches of Articles of the United Nations Convention on the Rights of Persons with Disabilities ([UNCRPD](#)) and people with multiple unmet social care needs.

This report describes four complex cases and the work done by the Community Navigator to support the individuals involved. The evidence is drawn from contemporaneous notes made by the Community Navigator. The four cases are anonymised, with pseudonyms being used. They describe the position of the individuals over a fixed period of time, up to 05 August 2022. They demonstrate situations that should not have been able to arise, and the painstaking casework required to then make a difference. The four cases also indicate how easily rights enshrined in Articles of the [UNCRPD](#) can be breached and demonstrate unmet needs for health and social care support. These are set out at the end of each case. Unmet needs in adult social care is the subject of a wider literature review also arising from this Future Visions project (Zarkou N. & Brunner, R., March 2023).

The work of the GDA Community Navigator

In 2022-23, the Community Navigator has supported over 110 disabled people, from teenagers to people in their 90s. Most referrals come from the wider GDA team, notably staff that support disabled people with wellbeing and welfare rights. Getting 'alongside' the person in a trusting relationship is the first step in understanding and defining the problem. As referrals often come via an existing trusted relationship with GDA this helps the Navigator get a speedy understanding of the issue(s) affecting someone, and quickly gain consent to act on their behalf.

The Community Navigator gains an understanding of the facts of each person's story and their efforts to gain support from social care and related organisations. Community Navigator clients face problems that should be attended to by a variety of agencies, in and beyond social care. These commonly include social care providers, social work professionals, G.P and other NHS services, housing, mental health services, welfare rights and financial services, and local authority departments. The Community Navigator takes up their case with their consent, advocating and negotiating on the person's behalf, and/or supporting self-advocacy, often across a range of

services. The Community Navigator also often provides practical and emotional support to the individual, alongside the elements of advocacy.

The four cases below demonstrate the value of the Community Navigator as a wide-ranging, in-depth, time-rich role, that is (sadly) necessary for some disabled people with complex lives and multiple barriers to get what they need from the social care system and related services. The extensive remit of the Community Navigator is distinct, for example, from the more limited temporal and geographical 'signposting' support provided by Community Link Workers based in some GP services. The four cases suggest that there is a current, ongoing need for cross-cutting advocacy to support disabled people with complex lives to have their human rights fulfilled by the social care system, and for unmet social care needs to be satisfied. While the engagement of the Community Navigator with statutory and third sector services supports those services to better enact social care to support the individuals concerned, it also offers the potential for services to learn and so better deliver human rights and independent living outcomes for disabled people more widely.

Three of the four cases relate to individuals who were referred to the Community Navigator via Wellbeing Advisers from GDA's Wellbeing service. Advisers were concerned about the situations in which these individuals were living and the impact on their mental health. In addition, the Wellbeing Advisers highlighted the individuals' lack of capacity to cope and deal with the services involved to address these concerns by themselves. The fourth person was an existing GDA member who contacted the organisation to ask for help, and were directly referred to the Community Navigator.

Case 1: Abigail

Abigail is a woman in her late 80's living in sheltered accommodation. She is a stroke survivor with reduced mobility, balance, and arm dexterity. She also has high blood pressure, oedema, glaucoma, and anxiety. Abigail has used statutory support services including home care, and third sector support, for over two years. When she contacted GDA, Abigail had been unwell and felt very forgetful. Social care supported her to shower on two days a week. On the days she had no care, Abigail did not dress, as this was too difficult for her, and was only able to give herself an upper body wash. She also had problems sleeping due to uncontrolled body pain, and sometimes fell asleep in the day in her chair, so missing the person who delivered her meal. She told GDA that she found the situation upsetting but hated to ask for anything or bother anyone, and felt she was a burden. She wanted more support and gave the Community Navigator consent to advocate on her behalf. With Abigail's support needs intersecting health and social care, the Community Navigator contacted Abigail's GP to request a medication review. She also

requested a re-assessment from her home care providers. The re-assessment happened within days, leading to homecare offering Abigail daily support and a new Occupational Therapy assessment. After persistent advocacy from the Community Navigator, GP services also visited Abigail and prescribed medication to help with oedema and glaucoma.

Alongside these issues, for several months Abigail could not leave her house as she had a broken wheelchair. This meant that when her family visited, which was Abigail's only opportunity to leave the house, she was unable to go out with them. Abigail is sociable and found this isolation depressing. The Community Navigator contacted the wheelchair company, who said they could not fix it without knowing Abigail's weight. Due to her impairments, Abigail needed support to weigh herself. The Community Navigator asked her GP, and the district nursing team, but neither could offer that support. The Community Navigator then contacted the Occupational Therapy team, who had not seen Abigail for a long time, but offered to visit Abigail with an appropriate scale. This was done, and her wheelchair was eventually replaced, and Abigail was able to go out with her family. Abigail remained anxious about most things and continued to find life difficult.

Human rights implications. This case demonstrates in a very simple way, how rights enshrined in the [UNCPRD](#) can be breached. This case indicates several prima facie breaches of Articles, including rights to independent living (Article 19), personal mobility (Article 20), respect for home and family (Article 23), and rights to participation (Articles 29 and 30).

Unmet needs. This case has unmet needs that straddle health and social care. In terms of health, they include the unmet need for support to actively manage a variety of conditions. In relation to social care, unmet needs include activities relating to personal care and mobility inside the home that are basic to daily living, including personal hygiene and dressing. Outside the home, they include the ability to get around, live independently, and have a family life. There are also unmet socio-emotional needs including needs for belonging, social interaction, social support, and autonomy.

Case 2: Bridget

Bridget is in her 30s and approached GDA for support regarding her care and her tenancy. She had experienced physical impairments and mental health issues for many years, lived in adapted accommodation, and used statutory services. She was recently bereaved, resulting in significant, complex, and sensitive changes in her needs for support. Bridget currently received 28 hours of care per week for essential personal care. Her care provider had recently changed. Bridget was unhappy with the new provider and wanted to

explore alternatives. Her current carers did not stay for their allotted time, and did not appear to have been passed any prior information on her care needs or on how to access her home. She had also experienced pain when they moved and assisted her. She wanted to have a choice in how her care should be delivered, and who by. She also wanted clear information on her budget to enable her to pay for additional care, but social services had not responded to her requests for this.

In the short-term, to enable new carers to understand Bridget's care needs, the Community Navigator supported Bridget to make a document of information to be kept in the house, including special instructions on moving and assisting her. The Community Navigator also contacted the care provider to ensure that carers understood how to access Bridget's property, so not wasting time gaining entry.

In the medium-term, Bridget was seeking a move to adapted accommodation closer to her family, so that the family could better support her. Social Work had agreed to make housing applications on Bridget's behalf. Bridget needed an Occupational Health and social work assessment. After several months of persistent Community Navigator advocacy, an updated social work assessment and review of needs was agreed. Bridget had an Occupational Therapy assessment of the difficulties around her care, with support from her family noted as essential support, and an application for a house move being supported.

During this time, Bridget continued to be unhappy with her carers, including examples of leaving food out of her reach, washing her commode in the bathroom sink despite being asked on multiple occasions to use the shower and toilet for this, and being abrasive in manner. Bridget's mental health also worsened, resulting in the Community Navigator contacting statutory mental health services on her behalf. At the time of recording in case notes (05 August 2022), Bridget was still waiting for the social work assessment to establish how many hours of support she is entitled to, and so to allow her to be able to apply for Self-Directed Support, to seek an alternative care provider of her own choice, and to pursue her housing move. The Community Navigator was keeping in touch with Bridget regularly to give ongoing support.

Human Rights implications. GDA needed to provide significant, ongoing advocacy to support Bridget with her decision-making, in a complex situation, and in the context of a major life event - and then to advocate her needs and wishes with multiple social care agencies. This case indicates several prima facie breaches of [UNCRPD](#) rights, including the right to independent living (Article 19), personal mobility (Article 20), information (Article 21), respect for home and family (Article 23).

Unmet needs. This case has unmet needs for dignity in social care, consistency in social care, being heard by social care, and for being cared for without pain. There are unmet mental health needs. There is an unmet need for information on the social care budget; this detracts autonomy over their care package and the potential for moving house and fulfilling unmet socio-emotional needs including needs for belonging, social interaction, social support, and having a better family life.

Case 3: Carrie

Carrie is a woman in her 50's, living independently with care support, who had experienced physical pain and fatigue since childhood, in addition to having a significant mental health diagnosis. She had used statutory services, including care services, for many years. Carrie got in touch with GDA as she was unhappy with her care, reporting unsatisfactory moving and assisting and unsuitable visit times. She described the care workers as being subjected to work stress that they transfer into the way they work with her. Her care visit to be supported to shower each day was scheduled between 7.30am and 9.30am. However, this meant that she needed to take her medication at 5.30am in order to manage the pain of being touched and moved. Carrie had asked for a later morning slot, but had been told by the care provider that afternoon was the only alternative they could offer. On discussion with the Community Navigator, Carrie's concerns were:

- Care delivery changes being communicated to her by care workers with varying accuracy, causing stress and anxiety.
- No communication from care organisers regarding changes in the timings or extent of care after a review meeting.
- The Care Plan in Carrie's home being inconsistent with the Care Plan on the staff electronic tablets.

The Community Navigator contacted Carrie's social worker on her behalf, who agreed to put points to the care provider: Carrie would like a late morning slot for her shower, and any care changes should be communicated to Carrie at appropriate times e.g. after review meetings. Carrie told the Community Navigator that she was happy to have the stress of communicating her anxieties taken off her. However, Carrie was still experiencing pain when being assisted to move, and also when carers sometimes touched her with affection (e.g. holding her hand). She knew this was meant with a good heart, but it led to her feeling anxious when they arrived. The Community Navigator supported Carrie with making a colourful and friendly notice to inform visitors of Carrie's varying physical pain on contact.

Human Rights implications. The case underlines the importance of Article 3(1) [UNCRPD](#) – ‘*Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons*’, as it shows that the right to choice and control over what is reasonable care (e.g. having a shower at a suitable morning time, rather than in the afternoon) can be in conflict with care provider ‘time slot’ practices and constraints, and resource management decisions.

Unmet needs. This case indicates unmet needs for dignity in social care, consistency in social care, being heard by social care, and for being cared for without pain. There is an unmet need for consistent information on their social care package, including timely updates following reviews; these detriment Carrie’s autonomy over her care package.

Case 4: Dorothy

Dorothy is in her 70s and is a wheelchair user who had used statutory support, including social work and mental health services, for many years. Dorothy had waited over a year for an Occupational Therapy assessment for an access ramp to her home. This meant she was unable to use the budget she had been allocated for a wheelchair to get out of the house, and she could not join her family on outings or shopping. Dorothy described this to the Community Navigator as feeling ‘*imprisoned*’. Nine months after the Occupational Therapy assessment, still no action had been taken. After making several calls to advocate on Dorothy’s behalf, the Community Navigator was informed that the ramp would soon be authorised. Dorothy would hear shortly after that about the installation date.

Human Rights implications. This case indicates several prima facie breaches of [UNCRPD](#) Articles, including rights to independent living (Article 19), personal mobility (Article 20), respect for home and family (Article 23), and rights to participation (Articles 29 and 30).

Unmet needs. Several independent living activities are inaccessible for the need of a ramp, including the ability to leave the house, to meet people, and to shop. This also detracts socio-emotional needs, including needs for belonging, social interaction, social support, and having a better family life.

Conclusion

The cases show how disabled people rely on timely and appropriate support from health and social care services, and wider systems, in order to actualise independent living. The cases also demonstrate the need for ongoing Community Navigator support to enable disabled people to navigate social care, health care and related services. They show how hard it can be to navigate these systems on your own behalf. Achieving a successful outcome is founded on gaining a trusted account of what has happened to the individual disabled person, in order to express their case with credibility to social care, health and related services. They demonstrate that the work of satisfying health and social care support needs can cut across multiple services. The evidence suggests that, to be effective, Community Navigator support needs to not be time-bound or to fit with an oversimplified model, because each lived experience – of impairments, barriers, needs, wishes, and service usage - is unique and each person needs a tailored intervention.

The combination of independent advocacy, brokering and practical support offered by the Community Navigator within the ecosystem of GDA can push services towards satisfying unmet needs and upholding human rights, and so enabling independent living. However, these cases indicate how human rights enshrined in Articles of the [UNCRPD](#) can easily be breached. However, the cases also highlight wider ‘natural justice’ concerns, such as the right to timeliness and the right to independent advocacy, that should be central in Scotland’s strategic thinking about current and future rights to social care.