

Growing Older Planning Ahead

Healthwatch Darlington
November 2023

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About Healthwatch Darlington

Healthwatch Darlington is the health and social care champion for people who live and work in the borough of Darlington. As an independent statutory body, we have the power to make sure NHS leaders and other decision makers listen to people's feedback to improve standards of care.

We use feedback to better understand the challenges facing the NHS and other care providers locally, to make sure people's experiences improve health and care services for everyone.

We are here to listen to the issues that really matter to our local communities and to hear about people's experiences of using health and social care services.

We are entirely independent and impartial, and any information shared with us is confidential.

The Tees Valley Healthwatch Network is a collaboration of 5 autonomous Healthwatch who, when circumstances require it, work together to support, and promote the experiences of users of health and care services in the Tees Valley. It comprises the following Healthwatch:

Darlington

Hartlepool

Middlesbrough

Redcar and Cleveland

Stockton on Tees

Executive summary

The North East and North Cumbria Integrated Care Board (NENC ICB) is the statutory NHS organisation which is responsible for developing plans for arranging for the provision of health services in the Tees Valley. Darlington is one of five local authorities in the Tees Valley area.

At Healthwatch Darlington we welcomed this collaboration with our neighbouring Healthwatch to provide insight to the NENC ICB, to give them a greater understanding of the needs of people with a learning disability, aged 40+, so they can improve the planning process when families can no longer support their family member to stay at home.

We asked carers, those they care for, and professionals who support them to tell us what is important to them, and what support they need to live a happy and healthy life. This report relates to the feedback and insight in the Darlington area and has contributed to a wider Tees Valley report.

All three groups of cared for, carers and professionals agreed the best outcomes occurred when appropriately trained support staff were available to help individuals live an independent life and there was help in maintaining a good social network of friends and family, including suitable transport and good community facilities to meet people with similar interests and needs.

To help achieve this goal we have offered four recommendations based on our insight, in the following areas:

1. Good communication.
2. The importance of location.
3. Timely, clear, and phased transition planning.
4. Dedicated skills training and awareness raising of existing support.

We look forward to continuing to support Darlington Borough Council as well as the wider NENC ICB representing Tees Valley, to ensure the voice of those who are impacted by this service continues to be listened to.

Michelle Thompson BEM

Chief Executive Officer, Healthwatch Darlington

Introduction

Tees Valley Healthwatch Network worked in partnership with North East Commissioning Support on behalf of the North East and North Cumbria Integrated Care Board (NENC ICB).

Our aim is to deliver a local review in response to the national requirement to improve planning process when families can no longer support their family member to stay at home.

This is important because without adequate planning and preparation, when families can no longer support their family member to stay at home, there could be an increase in crisis placements. There is limited information available regarding experiences of family carers who are anxious and afraid about the future for their son or daughter and how this will affect a person with a learning disability.

There is little research regarding the lives of older people with learning disabilities, such as health issues, the illness or death of a family member and how this can affect a person with a learning disability and impact on their behaviour.

The particular focus of this project is to improve support for family, carers, and older people with learning disability (aged 40+ to reflect the early onset of chronic health conditions such as dementia) by producing effective recommendations.

This report focuses on the key societal challenges of:

- meeting the needs of people (and their carers) with learning disabilities **aged 40 and over** with increasing life expectancy.
- transition planning for people with learning disabilities as their carers age.
- the health and social care system's response to ageing carer breakdown / crisis arrangements.
- service planning to ensure sufficiency and adequacy of provision to meet complex needs.
- support and guidance for ageing carers.
- effective navigation of appropriate pathways for the cohort of older people with learning disabilities.
- assessment of risk of social isolation and loneliness for older people with learning disabilities.
- identification of inequities in the mental health and physical needs of this cohort.

Methodology

We agreed a standard set of survey questions across all five participating teams in the Tees Valley Healthwatch Network, with the North East Commissioning Support team. Our questions sought to discover:

- How people feel they are currently involved in the planning of their own future care needs as they grow older.
- If carers feel able to discuss how their child will be supported when they are no longer able to care for them.
- How carers want to be involved in planning for when they can no longer provide care for a child, when it should start and carers expectations of health and social care services.
- A baseline of local people's current knowledge of these services.
- What good looks and feels like.

Three surveys were created to capture data from carers, workers and any cared for person. The intention being to capture data on what is and isn't currently working with existing services, find out what individuals and carers want to see and improve services for older people.

We sent out email invitations to all local groups, professionals, Darlington Borough Council, and the voluntary and community sector. We used our social media platforms to regularly promote our three surveys. We distributed posters with QR codes for individuals to complete at their convenience.

We listened to feedback that cared for survey was too long and offered help to complete. We also decided to run focus groups, with a smaller number of questions.

The project ran from June until October.

Visits and focus groups

Making Sense Together Event on 30th August in Darlington Market Square. Approximately 200 people attended. Some surveys were completed on the day, and some taken away.

We visited the **Learning Impairment Network** on 6th September. It was run by Darlington Association on Disability (DAD), which we attend regularly. The network were good enough to grant us permission to record the data taken on the day and we thank them for that. Approximately 35 people attended which includes a mixture of The Peoples

Parliament, representatives from the Independent Living Hub, DAD staff, Darlington Borough Council staff including Social Care Direct and some voluntary organisations.

We attended a weekly social evening of **Gateway Club Darlington** on 7th September to support completion of our survey. Approximately 100 people attended. The social event was fabulous, and the Club were very approachable and welcoming.

Focus Group held with **Darlington Association on Disability** (DAD) group on 4th October 2023, who kindly agreed to us attending their Wednesday group where we spoke to 7 individuals who helped us to answer our questions.

We held a focus group with **The Independent Living Hub** on 9th October with 14 attendees. The group were all very young and still lived at home with their parents or carers. We got some great information but their experience of potentially moving out of home was limited.

We held a focus group with **The Hive Darlington** on 18th October with 5 attendees and their support workers.

Demographics

A full demographic breakdown of participants who completed a survey is available in Appendix One.

Survey findings: Summary

What matters most to people in Darlington

The **cared for** person told us that living in a nice house in a nice quiet area, with nice neighbours was most important to them. They liked being nearby family, friends, shops, and good transport links. They valued their independence with the freedom to make their own choices, be listened to and understood. Feeling safe and retaining their independence was also important. Those in supported living appreciated the on-site support they received.

They most needed help with administrative tasks such as filling in forms, managing their money and benefits and making phone calls, transport tasks such as getting to activities or appointments, and household tasks such as cleaning the house, washing clothes, making food and drinks and shopping. They told us that to live a healthy and happy life as they get older, they need help and support in these areas as well as support to manage their health, and emotional support when they feel anxious about life.

They also would like support in the areas that make them happy such as maintaining a good social network of friends and family with good community facilities to meet people with similar interests and needs.

Carers told us they worried about the person they cared for, as they get older, being able to manage their health needs, live independently, manage financially, have limited social opportunities, be lonely, have a lack of support services and suitable accommodation, not being understood, and accepted. In summary, the areas that the cared for participants told us was important to them, and where they needed support to live a happy and healthy life.

Despite their worries, 32% of carers did not know who to speak to about their concerns. The majority, 80%, did want to be included in future planning to ensure professional advice was obtained and understood, the carer felt fully informed, they could get involved in the organisation and coordination of future care, and generally support their cared for person to let them know they are supported in discussions and decision making.

Carers provided a list of services they were aware of to support the cared for as they got older – but a third of carers said they didn't think there was any support available.

The support they would like to see was financial, healthcare, family support service, social care, and day care.

Improvements carers would like to see were strengthening social care support, more support for carers, more financial and legal support, improved medical resources, and more diverse accommodation options.

There was no universal clarity within the **professional** responses around the current process for moving older people (aged 40+) with a learning disability into a new home. They rated the process average. They told us that involving the person and their families / carers in the planning, joint working between services and planning ahead worked well, which supports our insight that 80% of carers want to be involved in planning care. More choice of appropriate accommodation, more resources in terms of trained staff with better communication between all parties concerned in the move were areas that needed improvement.

For older carers who were no longer able to care for their loved ones, the professionals told us there were limited options available for support. They could refer the carers to social care or the NHS for a carers assessment and a care plan or arrange respite care.

The professionals told us gaps in services were lack of trained staff, a lack of choice, a lack of understanding of needs, lack of available accessible information, and a lengthy process.

In an ideal support service professionals told us they would like to see improved communication, more trained support staff, a better process, greater choice and more peer and community support.

In summary there was consistency across the 3 surveys. We have outlined a clear idea of what is important to the cared for, and what they need support with to live a happy and healthy life. This supports what carers tell us are their greatest concerns for their loved ones as they get older – that this level of support and care can be maintained when they are no longer able to provide that care.

We also have clarity from professionals about what they know to work well and the improvements that can be made to minimise the gaps in care.

Full details of the survey responses can be found in Appendix Two.

Local Authority Position Statement

Darlington borough council

Darlington Borough Council's market position statement is set out in full here: <https://northeastmarketpositionstatement.co.uk/intro/#panel-darlington>. We highlight some of their key messages below.

"Darlington Borough Council's future commissioning aims, and vision will be focused on changing behaviours to promote independence developing evidence based early interventions to prevent peoples care needs increasing and devising new delivery models through joint work with our partners."

"There is a vibrant care and support sector within Darlington, but the successful implementation of the ongoing ambitious transformation programme being implemented across Adult Services will rely on continued innovative joint working with individuals and their families and carers, partners in the public sector, in businesses, in the voluntary sector, and in our communities."

"We seek feedback from people directly in receipt of current services and these views are an integral part of all service reviews. In this way we can be assured that the support which we commission is being delivered effectively and is achieving the required outcomes. We work closely with our commissioned Healthwatch provider and use the information gathered from service users as part of their "Enter and View" visits and themed enquiries to help deliver future service improvements."

Conclusion

We wanted to understand the issues and aspirations around the planning process when families can no longer support their family member to stay at home from three different perspectives: the cared for, the carer and the professional viewpoint. As set out in our methodology, our survey sought to provide insight in the following areas:

1. **How people feel they are currently involved in the planning of their own future care needs as they grow older.** We found that there was a mixed response regarding levels of involvement dependent upon personal experience. There was however general agreement that the process worked well when trained staff with good interpersonal and communication skills helped individuals and carers navigate the service pathways.
2. **If carers feel able to discuss how their child will be supported when they are no longer able to care for them.** Many carers did know who to discuss the future with and had started that conversation. Some did not know but were willing to have that discussion suggesting further clarity around the process is needed.
3. **How carers want to be involved in planning for when they can no longer provide care for a child, when it should start and carers expectations of health and social care services.** Our carers told us they do want to be involved in planning for when they can no longer provide care for their loved one. There was no definitive agreement to when this should start, it was considered very much dependent upon the capacity of the individual concerned.
4. **A baseline of local people's current knowledge of these services.** Carers expectations and knowledge of health and social care services were mixed depending upon experience. There were a number of services mentioned, but some respondents had limited awareness suggesting improved communication and targeted promotion of services available was needed to raise awareness.
5. **What good looks and feels like.** All three groups of cared for, carers and professionals agreed 'good' looked like having trained support to help individuals live an independent life. This support would provide help to manage health, emotional support for when the cared for feel anxious about life, help with household tasks, help with administrative tasks such as filling in forms and making appointments, and managing their finances, help in maintaining a good social network of friends and family, including suitable transport and good community facilities to meet people with similar interests and needs.

Recommendations

Our engagement has highlighted areas that could help to improve transition pathways. Valuable feedback received has informed the following recommendations:

1. **Communication:** A clear service pathway, with timely and appropriately communicated information in the planning process is key in supporting all three groups we engaged with. The process itself must be easy to understand to enable support workers to convey it to carers and the individuals they care for.
2. **Location.** The ability to stay within the locality, access local services, and have regular contact with family and friends is very important to carers and the individuals they care for and must be acknowledged in the planning process.
3. **Clear and phased transition plans.** A person-centred approach is important, involving those cared for at every stage of the process as well as their carers. Having accessible information and having a timely lead in to any transition such as visits and early discussions are areas our participants told us were important to them and should be included in any service pathway.
4. **Awareness / training.** Participants were clear in the areas they needed support with. Dedicated training packages to provide individuals with support and advice for administrative and household tasks is needed. Raising awareness and promotion of existing services would also be beneficial.

Response from North East and North Cumbria Integrated Care Board

The North East and North Cumbria ICB would like to thank Healthwatch for producing the Growing Older Planning Ahead report and everyone who took the time to provide feedback. The report gives a valuable insight into what is important to people and their carers as they plan for their future and helps highlight the journey we need to continue in partnership with those people at the heart of our work.

The ICB is committed to improving lives for everyone with a learning disability and their carers and we welcome the report, with its recommendations when planning for people and their future needs. The report will help steer decision making and we will continue to reflect on the recommendations when developing plans with stakeholders. The case studies also resonate with us with continued listening, hearing people's views and their experiences will support in our learning, to achieve better outcomes for people and their families.

Liz Whitehead

Commissioning Delivery Manager

County Durham and Tees Valley Mental Health and Learning Disability Partnership

Next steps

The insight gained from this engagement will be shared with the North East and North Cumbria Integrated Care Board, Darlington Borough Council commissioners and service providers, community and voluntary sector partners, Darlington Health and Wellbeing Board, and Healthwatch England to inform the future planning and delivery of services, which will help to improve support for family, carers, and older people with a learning disability.

Acknowledgements

Healthwatch Darlington thanks all service users, carers and professionals who have helped us to gather this valuable information, either by completing a survey or taking part in focus groups, workshops, and discussions to tell us about their experiences, including:

- Learning Impairment Network
- Darlington Association on Disability (DAD)
- Gateway Club Darlington
- The Independent Living Hub
- The Hive Darlington

The information you have provided has been vital in helping us to ensure the voice of service users influence the improved delivery of health and care services and is greatly appreciated.

Appendix One: Demographics

Age category	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%
17 or younger	-	-	-	-	7	27%
18 – 20 years	-	-	-	-	2	8%
21 – 29 years	-	-	9	36%	2	8%
30 – 39 years	2	25%	6	24%	-	
40 – 49 years	4	50%	3	12%	2	8%
50-59 years	1	12.5%	4	16%	1	4%
60 or older	1	12.5%	3	12%	12	45%
I don't want to say	-	-	-	-	-	

Gender	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%
Male	2	25%	10	40%	15	60%
Female	3	37.5%	14	56%	10	40%
Prefer not to say	-	-	1	4%	-	-
Prefer to self-describe	-	-	-	-	-	-
Did not respond	3	37.5%	-	-	-	-

Are you currently...	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%
Single, never married	5	62.5%	3	12%	10	40%
Married or domestic partnership	-	-	20	80%	13	52%
Divorced	-	-	1	4%	-	-
Separated	-	-	-	-	-	-
Widowed	-	-	-	-	1	4%
I don't want to say	1	12.5%	1	4%	1	4%
I don't know	-	-	-	-	-	-
Did not answer	2	25%	-	-	-	-

Can you tell us if you have any physical or mental health conditions? (Please tick as many as you like)	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%
Long-term standing illness or health condition such as: cancer, HIV, diabetes, chronic heart disease / circulatory conditions, high blood pressure, respiratory conditions (asthma), epilepsy, digestive conditions (e.g., irritable bowel syndrome (IBS) and Crohn's disease)	2	25%	5	25%	5	25%
Physical impairment or mobility issue such as: difficulty using your arms or using a wheelchair or crutches	-	-	3	12%	12	48%
Sensory loss such as: sight and hearing loss	-	-	10	40%	11	44%
Mental health conditions or illnesses such as: anxiety, depression, and eating disorders	-	-	5	20%	15	60%
Developmental conditions such as: Autism Spectrum Disorder (ASD), which includes Asperger syndrome, and Attention Deficit Hyperactivity Disorder (ADHD), Learning impairments e.g., dyslexia and processing issues	3	37.5%	2	8%	11	44%
Genetic conditions such as: Down syndrome and cystic fibrosis	1	12.5%	-	-	-	-
Prefer not to say	-	-	1	4%	2	8%
None	-	-	4	16%	-	-
Other	-	-	3	12%	-	-

Ethnic background:	Cared for person completing the survey themselves	%	Carers who completed the survey	Carer %	The person they care for	%
White						
White British	6	75%	24	96%	24	96%
Irish	-	-	-	-	-	-
Other	-	-	-	-	-	-
Asian / Asian British						
Indian	-	-	-	-	-	-
Pakistani	-	-	-	-	-	-
Bangladeshi	-	-	-	-	-	-
Any other Asian background	-	-	-	-	-	-
Mixed						
White and Black Caribbean	-	-	-	-	-	-
White and Black African	-	-	-	-	-	-
White and Asian	-	-	-	-	-	-
Any other mixed background	-	-	-	-	-	-
Black or Black British						
Caribbean	-	-	-	-	-	-
African	-	-	-	-	-	-
Any other Black background	-	-	-	-	-	-
Other ethnic group						
Chinese	-	-	-	-	-	-

I do not wish to disclose my ethnic origin	-	-	1	4%	1	4%
Other, please specify	-	-	-	-	-	-
Did not respond	2	25%	-	-	-	-

What do you consider your religion to be?	Cared for person who completed the survey themselves	%	Carers who completed the survey	%	The person they care for	%
No religion	3	37.5%	3	12%	4	16%
Christianity	1	12.5%	18	72%	18	72%
Buddhist	-	-	-	-	-	-
Hindu	-	-	-	-	-	-
Jewish	-	-	-	-	-	-
Muslim	-	-	-	-	-	-
Sikh	-	-	-	-	-	-
Other	-	-	3	12%	-	-
Prefer not to say	-	-	1	4%	2	8%
I don't know	1	12.5%	-	-	-	-
Did not respond	3	37.5%	-	-	1	4%

Appendix Two: Survey responses, full details

Survey 1: Cared for person

Note: We had 8 responses to our survey which were completed between 15th August 2023 and 27th October 2023.

71 attendees at our five focus groups held between 6th September 2023 and 18th October. The focus groups were based on the survey.

Responses below indicate whether responses were from the survey, focus groups or both.

Demographics in the appendices relate solely to the 8 people who completed our survey online.

We asked survey and focus group respondents to let us know who they lived with now.

	Supported living	With family (including their pet)	On their own	With their partner
Respondents	40 (51%)	24 (30%)	14 (18%)	1 (1%)

We asked survey and focus group respondents to list each thing they liked about where they lived now (number of responses in brackets).

Nice area (6) Quiet (3) Nice neighbours (2)	Nice house / ground floor flat / bungalow / garden (4)	Independence / freedom to make own choices (3)	Easy to walk to places / nearby shops / transport (3)
My family / friends (3)	Support (3): social worker, carers on site, office 24/7	Community centre / social lounge (2)	Sensory room
Security	Well respected member of the community	Able to have pets for companionship	Nothing

Within the focus groups, we also asked them what they did not like about where they lived now:

<p>Area not nice (2) Noisy (4) Other tenants (3)</p>	<p>Lack of choice and information to inform choice (8) sometimes leading to being housed out of the area</p>	<p>Lack of information, process is confusing (6), knowing who to talk to if there is a problem, lack of support (2) such as easy read and other accessibility support</p>	<p>Lack of understanding of needs, council don't listen, poor communication with those with learning impairment (4)</p>
<p>Don't feel safe (2), drugs</p>	<p>Gap in support when you do get a property (2), lack of communication between professionals</p>	<p>Need to be tech aware with email address and access to the website (2)</p>	<p>Landlords reluctant to make alterations</p>

One of the focus groups were particularly keen to understand if there is an allocated role in housing to support people with a learning impairment. If so, is there an option to meet face to face or a drop in option?

In general, those who lived in supported housing highlighted clarity of what is available support wise being a significant issue for them. They wanted to know how support is communicated effectively, including any changes. They also asked how housing know they are delivering the best possible support to people with a learning impairment, ensuring they are receiving the support and funding needed to stay as independent as possible.

We asked survey respondents and focus groups what they needed help with now.

Reading and writing (26) incl. filling out forms	Help with my money (25) incl. managing benefit deadlines	Making phone calls (24)	Going to activities (24)
Washing clothes (24)	Going to appointments (22)	Making food and drinks (19)	Shopping (13)
Jobs in the house (10) such as tidying up and cleaning	Keeping fit (10)	Seeing friends (10)	Getting washed (9)
Getting dressed (6)	Going to work (5)	Going to the toilet (5)	Other: Memory (prompting to do things) Emails and internet Medications

Participants told us that understanding people who had a different accent, such as those whose first language is not English, as well as being easily understood themselves was a considerable barrier to accessing services. Communication barriers often led them to lose confidence and ‘give up’.

We asked survey participants to tell us three things that made them happy.

Talking to people, going out (3)	Dancing / music (3)	Being with my friends (3)
TV / films / videogames (3)	Being with my family (3)	Animals (2)
Cup of tea (2)	Being understood (responding to my signs)	Walking Going to Sanctuary

We asked focus group participants to tell us what they would like to see as they get older, to help them live a healthy and happy life.

General support (15): health, physical, financial such as budgeting, emotional “if I feel frightened or anxious”, regular assessments, a good support worker, support in the community, access to staff in supported living, help making phone calls / filling forms / writing letters, having trust in your support, council, GPs, knowing what support there is and how to access it.

Social (12): social network, friends visiting, family nearby, good community centre nearby, going out, living with people with similar interests and needs

Feeling safe (11): nice quiet area, concerned about homelessness, loneliness, being stuck in hospital

Supported to have a suitable / nice home (9): quality, manageable size, clean and tidy, well maintained with timely repairs, own furniture, and appliances

Being listened to (9): not being rushed, residents’ meetings to share concerns, making own choices, being involved, allowing pets, choosing my support person, individual plan specific to me, clear communication lines to quickly resolve issues

Independence (5): having resources such as TV and games consoles, internet facilities, YouTube, feeling empowered to make decisions

We asked survey participants to let us know if they would like their own place to live, and if they did have their own place, would they like someone to live there with them. We also asked if they had their own place would they like to live somewhere close to where they live now.

	Would you like your own place to live	If you had your own place, would you like someone to live there with you?	Would you like to live close to where you live now?	Comments
Yes	No one responded ‘Yes’.			
No	3	2 said they would like someone to live there with them. 1 did not respond	All 3 said they would like to live close to where they live now.	-
Not sure	2	Both said they would like someone to live there with them and one said they would like a dog and someone to talk to who shares their interests.	Both said they would like to live close to where they live now – although one said, “not too close”.	One said they would like more space.
Did not respond	3	-	-	Already live in my own home If I did own my own home I would like my

				mum, dad, and dogs to live with me and be near to where I live now.
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We also asked if anyone had talked to them about where they might like to live in the future. 3 said yes, 3 said no, and 2 did not respond.

We asked if they moved to their own place in the future, what it was that they would find helpful.

Help to buy things I need for my new place (5)	Help to pack and move (5)	Show me how to use things in my new place (4)
Help me get to know my surroundings and my new neighbours (3)	Being involved in choosing where I live (3)	Having regular visitors (2)
Making new friends (2)	Having someone I can contact who supports me with what I need (2)	Taking part in activities (2)

We also asked if they had been offered a Health Check, and if so, had they attended it. 6 said yes, 1 said no, and 1 was unsure.

7 of the respondents said they had been to their Health Check.

We also asked if they had a Health Plan, and if so, what their Health Plan helps them to do.

4 said they did not have a Health Plan, 3 were unsure.

1 said they did have a Health Plan and said it helped them to attend appointments, control their diabetes, and help with their foot appointments.

Survey 2: Carers

25 carers responded between 11th July 2023 and 1st November 2023.

22 were responding on behalf of a parent, 2 for a friend, and 2 for their partner.

We asked respondents to let us know what they worried about when thinking of the person they cared for growing older.

Health (20): (of the cared for person) physical, mental and emotional.

Ability to live independently (15): keeping safe, trusting that they will be looked after by other people.

Financial issues (13): how will they afford to live reasonably, no grants in Darlington, lack of job opportunities.

Lack of social opportunities and loneliness (12)

Lack of services and accommodation (11): nothing for post 16 to support socialising, scarcity of accessible bungalows, poor transport options, moving into care, where they will live, lack of suitable housing.

Health (9): (of the carer) not being strong enough to care for them myself, who will help look after them after I am gone.

General care and support issues (9): maintaining a good diet

Understanding and acceptance (5): potential bullying, discrimination, not reaching their full potential due to judgement and lack of understanding, not being listened to, not having choices.

We asked if they knew who to discuss future care with, if they had discussed future options for the person they cared for, and if they wanted to be involved in the future planning of care arrangements. If they did, we asked then how they wanted to be involved.

8 carers did not know who to discuss future care with and had not discussed future options.

17 said they did know and had discussed options:

- 13 had discussed future options with a family member.
- 1 with a group called NESAT who ran the local Darlington protest in April.
- 1 with the person directly to understand their wishes.

One carer told us they had arranged lasting power of attorneys for health and finance and made wills. They told us they received no support from the doctor or the bank.

Another told us they had no confidence in adult social care system.

2 said they did not want to be involved in the future planning of care arrangements.

3 were unsure.

20 carers said they did want to be involved in the future planning of care arrangements for the person they cared for. They wanted to be involved in the following ways:

Seek professional advice (14): A professional assessment of need from a health care provider, social worker, or nursing specialist etc. Learn about available care options and resources so they can provide advice, guidance, and support on elderly / young person care.

Be informed (13): Research different care and nursing options, such as home care, nursing homes, independent living communities, and more. Research the pros and cons of these options and work with older adults to assess which option best suits their needs and preferences. Be informed about all work the parent carer forum and the local authority are doing regarding SEND, LD, caring, carers etc.

Organisation and coordination (11): Making sure they have a home to live in, letting our voices be heard through people like NESAT, making sure they get the right care.

General support (12): to aid communication and understanding, be present at meetings, help with form filling, creation of support plans, be there for them so that they know they are supported as much as possible, finance support.

Family discussion and negotiation (9)

Discussions and decision making (7): who the staff will be, accommodation they will live in and where it is. Finance and how and who will be responsible. Ask us what we need, what would best support our children and actually act. Communicate with those you care for to understand their hopes, preferences, and needs. Understand their expectations in terms of living environment, healthcare, social activities, etc., in order to develop an appropriate care plan for them. Options must meet the needs of the carer and the cared for. Given opportunity to voice our experiences and have multiple options not just one way of information gathering.

Carers also shared their concerns with us:

I do not know how to go about finding out what to put in place. I find it very difficult. (2)

The Local Authority only seem to want deal with crisis management. No confidence present services would be able to deliver the support to the standard currently given within the family.

From experience, once cared for is moved into supported accommodation all decision making is removed and financial arrangements become very complicated – effectively any family involvement is completely subjugated.

We also asked how old the person they cared for should be when discussions start about future care.

Age range	Carers	Comments
17 or younger	6	<p>Depends on the capacity and understanding of the individual. This is a blanket question which does not apply to all and does not take needs into consideration (this is part of the problem).</p> <p>At 17yrs old they would have a year left potentially of education and I would want to start looking at what future support they require then and how we go about getting that set up for them.</p> <p>There needs to be a plan in place a pathway, as something could happen to the carer that changes the present and it should be a smooth as possible transition.</p> <p>The younger the better so early intervention can be put in place so development and support opportunities can't be missed or overlooked.</p> <p>He can't make decisions easily.</p>
18 to 20	1	Worried about the child's youth and development.

21 to 29	3	This is difficult - when you are caring for someone who lacks capacity and therefore comprehension of the concept of being "cared for" it is practically impossible to start a direct conversation - you have to start with a series of "would you like to?" questions to try and build up a picture though not many positive outcomes - put this down to does not want routines/ surroundings/ people to change. I don't know I think it's something that upsets me so much and will upset my son I don't like to think about it as when I do I get very anxious.
40 to 49	1	Due to health problems.
50 to 59	2	We will be getting older, length of time it takes to get things in order. Would like to make sure decisions are in place before circumstances become an emergency.
60 to 69	11	No comments.
None selected	2	I haven't selected any as I don't think age should be a factor it should be when the care needs arise.

We asked what respondents' awareness is of services that are available to the person they care for as they get older.

Care agencies / third sector support (22): Family Support Service, Future Steps, Age UK, NESAT for advice, social events, community support.

Adult social services / social care / social worker (12)

Health care (12): GP / hospital

Nursing homes and independent living communities (9)

None (8)

Financial (3): direct payments, Education, Health, and Care Plan (EHCP) which protects them until 25

We also asked what support the person they care for receives now, and which of those they would like to see continue as the person gets older.

None (7)

Financial (4): Support worker via Direct payments, EHCP, DLA, carers allowance, day care

My support and other family members (3)

Community organisations and charities (2): Age UK, charity helplines

Family support service (9)

GP / hospital support (9)

Not known

The support they would like to see continue

Financial support	Health care	Family support service	Social care	Day care
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10 said the people they cared for do not presently receive help from support services.

We asked the carers how they are currently supported to manage the person they care for in respect of behaviours that challenge others, and how that could be improved.

20 said they receive no support, and 3 did not respond to this question. Others said: school, parent carer forum, other parents

When asked how this could be improved, carers told us:

Strengthen social care support (18) including psychological support for carers

More support for carers (10) including education and training, carers grants, emergency contact number to access help, providing a safe space for carer and person, more information (but not forced), emergency response team.

More financial and legal support (10)

Improve medical resources (9)

Provide more diverse accommodation options (9)

Understanding, tolerance, acceptance, empathy.

We asked if the person they care for is offered a Health Check every year, and if they do, did they attend and receive a Health Action Plan.

17 said yes and they did attend the appointment. 15 of those who attended had a Health Action Plan in place as a result of their health check.

5 said no.

3 were unsure

We asked if the person they care for is on the local learning disability register.

17 said yes.

4 were unsure.

4 said no.

And if the respondent accessed local carers services.

16 said yes.

9 said no.

Services accessed included:

Parent carer forum, home care services, community care services, telephone hotlines and counselling services, volunteer organisations and community support, carers association.

"I have a carers card however it does not work everywhere."

We also asked the carer if they had a carers assessment and if they were registered as a Carer at their GP Practice.

18 said yes, 7 said no.

22 were registered as a Carer with their GP, 3 were not.

When asked if the carer would like to make any other comments, responses included:

"Up to 18 the person cared for was very adequately supported and this carried on with a mixed education and social care provision up to age 26 when the package of care became unsuitable. No alternatives were offered, and the local authority effectively withdrew support informing me as the family were more than capable there was no further need for interventions though could always contact a duty social worker should it become too much!

"Strengthen financial and legal guidance and support for the elderly, including pension and benefit advice, universal and transparent long-term care insurance, and sound estate planning and probate services."

"Provide more information and education about elder services and resources, including online platforms, information brochures, community talks and more. Make sure older people and carers are aware of available support measures and their entitlements."

"It's not just learning disabilities that have issues have same when dementia is diagnosed."

"I arrange activities for my son as I have had social services out and they just said basically I can cope then when he was an adult, they said he had to refer himself which he can't speak on the phone, so I have no confidence in them."

"Formulate and implement relevant policies to safeguard the rights and well-being of the elderly. Strengthen the supervision and quality control of elderly services to ensure the reliability and transparency of services."

Survey 3: Professionals and support workers.

16 professionals and support workers who cover the Borough of Darlington responded to this survey between 13th June 2023 and 21st October 2023. Staff from the following organisations participated: Care TaylorMade, Dimensions, Groundwork North East & Cumbria, James Cook University Hospital, NECS, and Oaklea Trust. 7 of the 16 respondents identified as working for TEWV.

The range of roles undertaken by the professionals and support workers included:

Associate Practitioner, Behaviour Practitioner, Community LD Nurse (2), Community Project

Manager, Lifestyle Coordinator, Occupational Therapist, Registered Nurse, Senior Commissioning Support Officer, Senior Support Worker, Service Manager, Support Worker (2), and Residential Care Home (Adults) Team Manager.

We asked professionals and social workers to explain the current process for moving older people (aged 40+) with a learning disability to a new home, and to rate this process on a scale of 1 to 5. We asked them to explain what it was that worked well, and the top 3 areas that would benefit from improvement.

Only 8 of the 16 respondents explained the current process. A further 2 told us they were unsure of the process, and 3 told us that they would contact social care or the learning disabilities team for advice. Explanations included:

“By asking what their objective is to lead a happy life away from home, what they would like to see, type of people they could live with, locality and environment that would be suitable for their needs. Also, what services are provided in their locality i.e., transport, social, access to mental health professionals and close to hospitals and doctors.”

“They remain in our supported living house until we can no longer meet their needs.”

“Transition is client gets to know support staff before moving into the new home. Get to know personal info, move any items of furniture into the home so it's homely, regular updates with families.”

When asked to score the process on a scale of 1 to 5, over half of respondents chose the mid-way score of 3.

Score	Did not respond	1	2	3	4	5
Respondents	2	0	1	10	0	3

They told us what worked well (numbers in brackets represent number of responses):

- Involving the person in the planning, understanding their needs and wishes (8).
- Joint working between services (5).
- Planning ahead (3).
- Involvement of the carer / family (3).
- Building positive relationships between all parties concerned (2).
- Living close to town centre, near to amenities and shops (2).

They told us what needed improvement:

- More choice of appropriate supported accommodation in Darlington (8).
- More resources in terms of trained staff to support a successful transition to a new home (7).
- More robust providers to support complex cases with trained staff following care plans (4).

- Better communication between all concerned parties (3).
- Earlier planning (3).
- Raising awareness via signposting information (2).

We asked respondents to tell us how older carers, who are no longer able to support those they care for, are supported for themselves.

3 participants did not respond to this question.

3 told us there were limited opportunities / support to address real needs.

3 said they would make referrals to social services and the NHS.

3 mentioned registering as carers with their GP and having carers assessments and care plans.

2 mentioned respite care.

2 mentioned Carers Together and having an emergency care card.

1 said the work from 'you care we care' was invaluable.

Comments included:

"A Social Worker is possibly involved, emotionally and psychologically I'm not sure what support they may or may not receive during this difficult time bearing in mind they may also be quite elderly themselves."

"By offering respite services for the people they look after, review by social services, offering more help i.e., domiciliary care services. Access to funding and help. Meals on wheels, carers assessments, involvement from social care, respite options, support into the home."

"Reactive rather than proactive."

"Not much at all, older carers are often left to get on with it and have little support available to them if they can no longer care for their loved one which can leave them with a loss of purpose."

"Whatever support they can source...if they can."

We asked what current statutory services support older people (aged 40+) with a learning disability when leaving home for the first time.

Responses included:

Social services (6)

Adult social care transition team (3)

Occupational Therapy teams (3)

Support workers who sit within LD teams (2)

NHS Community Teams (2)

Don't know (2)

Housing teams. (2)

Local Authority Community Teams.

Two respondents quoted the Care Act 2014 as the legal framework for protecting vulnerable people, enabling a service user to have an assessment in their own right.

We also asked what current services support a Carer of an older person with a learning disability as they age. We encouraged respondents to give multiple answers.

Responses included:

Respite / short breaks (4)	Social services (4)	Carer support groups (4)	Carers Together (3)	Occupational Therapy / Physiotherapy / SALT (3)
Day Care Services (3)	Carers assessments (2)	LD community nursing team (2)	GP (2)	Voluntary organisations (2)
Housing	Private services	Home help	Direct payments	Meals on Wheels

We asked the professionals and support workers to tell us about gaps in current service provision for older people (40+) with a learning disability when leaving home for the first time? They were encouraged to give multiple responses.

Staff: Lack of domiciliary home care staff to support service user to integrate within the community (4). Dedicated person to help with the transition (3)

Choice: Lack of choice, limited availability of properties to match the level of need (6)

Understanding: More person-centred care – listen to the family, individual, and carers (4). More social opportunities to prevent carer breakdown (2)

Information: Lack of information given or given in the right way to support the persons understanding to enable the person to make the right choices so that it's a successful move (2)

Process: Transition process too long sometimes (2)

We asked what elements of care would be included in an ideal support service for older people with a learning disability to move out of their current home. Respondents were encouraged to give multiple responses.

Communication: A holistic support package that keeps family members involved at all stages (1). Person centred planning with intense communication with family and the person (1).

Support staff: More trained staff – better staffing ratios (4). A personal support worker to guide through every step (1). A transition team with 24 accessibility (1). Ongoing training and support (1). Supported living (1). Nursing care (1).

Process: Familiarisation and supported phased move out of home at their pace, taster sessions in new environment (6). Personal care (3). Dementia awareness (1). Creative lifestyle plan (1). They know how to be safe inside their home (1). Moving handling equipment (1). Flexible (1). No regimentation. Flexibility for families at all times. This will be a new home not just accommodation (1).

Choice: Choice and control of a number of different options (3). Service users choose the staff to help support them (1). Choices around making new environment their own (1). Decent standard (1). Good outdoor space (1).

Peer support: Access to accommodation with peers in a variety of settings (1). Peer mentoring (1). 'Friendshipping' before they move with those whom they will live with (1).

Community: Integration opportunities within the wider community (2). Possible opportunity for family to stop overnight with the person if needed (1).

Financial support (2)

Planning: Proactive physical needs/mobility/accessibility planning (1).

We also asked how respondents ensured every older person with a learning disability is offered an annual health check, and if someone does not attend if they find out why, and if they do attend if they are always given a Health Action Plan.

Responses to ensuring annual health checks were offered:

11 told us this was the responsibility of another service such as GP, social workers, community nurses, or other support staff.

2 said there was a follow up process in place after the automated recall was made.

1 said they would check reasonable adjustments were in place.

1 said it was checked on monitoring visits to services.

8 respondents said if someone did not attend their health check, they would find out why. 4 said they would not, as they did not have the follow-on relationship and capability to follow up. 4 did not respond to the question.

4 respondents said older people with a learning disability were always given a Health Action Plan (HAP). 6 responded negatively. 6 did not respond to this question. One respondent said it was 'hit and miss' and relies on proactive family members or carer support whether a HAP was issued. Another said it was not their role and the GP responsibility.

Respondents told us that where a HAP was issued, access was given to the person with the learning disability, their care provider, carers, family, and staff.

We asked for examples of good practice in residential supported living and family support services that support interventions for older people with learning disabilities (and their family / carers) with behaviours that challenge others. We encouraged multiple responses.

Training: By qualified SEND practitioners is essential (3). Positive Behaviour Support (PBS) training (5). Distraction techniques. De-escalating. Removal from situation.

Process: Risk assessments. Safeguarding. Documentation. Care plan. Quality of life support from the community learning disabilities team.

Communication: Keep family informed. Regular meetings regarding residents. Keep social worker informed. Partnership working between health and social care.

Reviews: Regular. Deprivation of Liberty (DOLs) review. Decision Support Tool (DST) reviews.

Finally, we asked who provides independent advocacy for carers and the person they care for in their area.

There were only 4 responses to this question.

“Advocacy service.”

“DAD in Darlington.”

“Darlington borough council.”

“Who knows. But families often don't know what advocacy is never mind where to find it.”

When we gave respondents the opportunity to provide any further comments, one responded:

Older people with a learning disability living with family are frequently forgotten about unless there are problems or concerns with their health, behaviour, home situation etc. It's usually those who are well known to social services that get all the attention. They are the forgotten people. Families who just get on with it without a fuss until carer breakdown happens, or death/hospitalisation of a carer/family member/ parent. Then it's crisis management. Lack of appropriate accommodation. Still in the Dark Ages in Darlington. So much more can be done.



healthwatch

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