healthwatch Middlesbrough

healthwatch Redcar and Cleveland

Growing Older Planning Ahead

Healthwatch South Tees
November 2023

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About Healthwatch South Tees

Healthwatch South Tees, the operating name for Healthwatch Middlesbrough and Healthwatch Redcar and Cleveland, is the health and social care champion for people who live and work in South Tees. 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 five 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 local Healthwatch:

Darlington

Hartlepool

Middlesbrough

Redcar and Cleveland

Stockton on Tees

Executive summary

South Tees is amongst the 10% most deprived areas in the country. Based on data from the 2021 census, out of 153 local authority areas, Middlesbrough is ranked the fifth most deprived in England and Redcar and Cleveland is ranked 31st. The Middlesbrough population ranks the highest nationally in terms of deprivation and Redcar & Cleveland is ranked 28th. However 47% of the Redcar and Cleveland age 16-64 population was economically inactive, the seventh highest in the country.

Within this report you will find how we approached this targeted piece of engagement, who we spoke to and their responses. As we cover two local authority areas, we have included responses separately for each one and combined themes, where relevant, for commissioners and service delivery to consider when providing support to these communities in each area, as well as across South Tees.

You will also find a case study that we have included to add richer context to the information found in this report, as well as recommendations for the future planning of for the whole health and care landscape for these targeted groups.

There are responses from both local authorities that highlight how they offer support whilst working within the Care Act 2014 and their consideration for NICE Guidelines (2018). In addition to this you will also find a response from our North East and North Cumbria (NENC) Integrated Care Board (ICB) detailing how they will use information gathered from our engagement to inform and influence their planning across the region and what the next steps will be.

Finally, we have included all of the demographic information separately for both Middlesbrough and Redcar and Cleveland as an appendix for your information. This will demonstrate the diversity of the people who contributed to this analysis within this report.

The following tables represent the baseline estimates for people predicted to have a learning disability for both local authority areas.

Please note the discrepancy between the predicted numbers shown in the tables and the numbers given to us by each local authority for our mail outs. This only confirms that not all of this community are engaged with social care services for support as highlighted within this report.

LD - Baseline estimates

People predicted to have a learning disability, by age.

Redcar & Cleveland	2020	2021	2022	2023	2024
People aged 18-24	259	254	251	248	250
People aged 25-34	411	408	408	403	401
People aged 35-44	360	370	382	390	398
People aged 45-54	421	405	391	378	366
People aged 55-64	450	459	468	468	468
People aged 65-74	366	366	360	360	364
People aged 75-84	217	224	239	245	252
People aged 85	75	77	79	83	85
Total population aged 18 and over predicted to have a learning disability	**2,559**	**2,563**	**2,579**	**2,575**	**2,583**

Middlesbrough	2020	2021	2022	2023	2024
People aged 18-24	397	389	383	383	385
People aged 25-	508	505	508	498	493
People aged 35-44	384	387	392	402	407
People aged 45-54	381	372	363	354	347
People aged 55-64	393	395	393	388	386
People aged 65-74	280	284	283	287	291
People aged 75-84	155	155	164	170	172
People aged 85	56	56	56	58	58
Total population aged 18 and over predicted to have a learning disability	**2,553**	**2,543**	**2,542**	**2,541**	**2,541**

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 the 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 family member 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 or 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 the family, carers and older people with a 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 years 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 Healthwatch 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.

We offered a wide range of methods to engage our targeted community ensuring accessibility for all. The methods we used are detailed below and were conducted during the period of **June to September 2023**.

- We commissioned an easy read version for the cared for person survey through Skills for People to ensure those with a learning disability could understand the information more easily.
- With the support of Middlesbrough Council and Redcar and Cleveland Borough Council we sent out information to all carers registered with the local authorities (LA's) who cared for an adult with a learning disability aged 30+ explaining our project and inviting their participation. We included a survey for the carer and an easy read survey for the cared for person and a stamped address envelope for them to return their completed surveys. 113 were sent out in Middlesbrough and 103 in Redcar and Cleveland.
- We contacted over 150 local organisations who support these communities to help us with access to those we required responses from.
- We held a digital workshop for relevant professionals working across South Tees through Teams and collected responses to the survey questions via Mentimeter.

- We distributed digital survey links for carers, professionals and adults with a learning disability, via our websites, social media platforms, ebulletins and directly with organisations that support these communities across South Tees.
- We distributed paper copies across South Tees of the carer survey and easy read versions with various organisations that support carers and adults with a learning disability.
- We held face to face consultations with carers and adults with a learning disability either at services they attended for support or within their home, across South Tees and produced a number of case studies with their information.
- We attended a variety of drop-ins and coffee mornings across South Tees to increase our reach to our targeted community.
- We produced videos as a promotional tool to encourage professionals and adults with a learning disability to engage in our activities and provide us with vital responses.
- We had a number of different radio interviews in order to promote and raise awareness of the project to ensure we reached those who may not be digitally connected.
- Life Learning Ltd Day Care supported us to engage one to one with adults with a severe learning disability in Redcar and Cleveland.
- We conducted telephone interviews with carers living in South Tees.
- We held focus groups with adults with a learning disability in partnership with the following organisations listed below across South Tees. Within these focus groups we delivered fun activities, where participants produced an image of their 'perfect house'. We found that by using arts as and crafts as a tool ensured participants fully understood what was being asked of them and could fully engage fully.
    - Independent Voices
    - Grenfell Club
    - Aapna
    - Middlesbrough First
    - Larchfield Community
    - 1st Enable
    - Cumberland Resource Centre

- We held carers consultations at:
    - Erimus carers meeting
    - Grenfell Club
    - Aapna

Demographics

During our period of engagement, we targeted the following groups of people:

- Adults with a learning disability aged 30+
- Carers of an adult with a learning disability
- Professionals who work to support carers and adults with a learning disability.

The table below shows the responses we received for each geographical area from each of our targeted groups.

	Middlesbrough	Redcar and Cleveland
Cared for person	62	35
Carers	25	17
Professionals	38	18
Totals	**125**	**70**

We utilised a variety of methods to ensure that our responses were representative of our local communities, including utilising our Community Champions who support a range of demographics across South Tees.

The most challenging group to engage with across both areas were carers of an adult with a learning disability.

Key statistics from the demographics showed:

- Most of the carers we spoke to were 60 or older and were female (Middlesbrough 68%, Redcar and Cleveland 71%)
- Both areas highlighted that many carers have a long-term health condition (Middlesbrough 36%, Redcar and Cleveland 12%) which may include a mental health condition such as anxiety or depression (Middlesbrough 12%, Redcar and Cleveland 24%)
- Responses from ethnic communities were low due to a cultural approach of looking after their families, however 10% of our feedback was from this demographic group. South Tees has a British Minority Ethnic population of 19.6% identified at Census 2021.

*A full demographic breakdown of survey responses can be found in **Appendix 1 & 2.***

Survey findings: Summary

What matters most to people in Middlesbrough and Redcar and Cleveland

Our summary includes not only the main themes from our engagement but also the barriers we experienced in collecting feedback, the barriers to those providing feedback and any emerging themes outside of the survey questions.

- During our engagement we came to understand that people who supported adults with a learning disability did not regard themselves as professionals. Initially, most of the responses we received from this cohort were from those working within the local authority, which informed us of the need to change the wording and approach.
- We experienced particular difficulty in engaging with carers of those with an adult with a learning disability. It is likely that this is due to their age (60-90 years old) and many are not digitally included.
- We found it difficult to find local groups that older carers attended.
- We received very little cooperation from carer organisations to identify these carers. Of those we spoke to, many were reluctant to give any information.
- Carers were hesitant to respond as it forces them to have these conversations with the person they cared for as they and didn't want to acknowledge that they may not be able to continue to give the level of care needed and, the person they care for may have to move out.
- In addition to this they thought that if they engaged with us their child would be taken away.
- One thing a carer did mention is having lost faith in any systems, being regularly get asked their opinion and asked to complete forms and then they hear nothing back.
- We were given more opportunities to access learning disability groups in Middlesbrough than Redcar and Cleveland.
- Not many opportunities to engage with adults with learning disabilities or carers from ethnic communities as we found that these communities look after their own.
- We didn't have relationships with individuals, which may have impacted on some people's willingness to speak. However, most people seemed to be happy that their support workers trusted us and therefore they would too!

Themes from engagement

Professionals

- Lack of suitable accommodation.
- Lack of support for both carers and individuals during this transition.
- Lack of advocacy for families.
- Planning conversations need to start earlier with families.
- Services need to work better together to improve coordination.
- There's a gap in services that support ageing carers.

Themes from the perspective of people with LD

- There were a number of cases where the cared for person became the carer for their parents due to the fact that they were the only sibling left at home. This had a significant adverse impact on both parties.
- Lack of ongoing formal assessments and forward planning led to deteriorating physical and emotional health issues for the cared for person and therefore emergency situations which could have been avoided.

"Mam had dementia and I was looking after her. She had a bell to call me, but she rang it all the time, so I turned it off. I came down and found mam had fallen... she had broken her hip." "I needed to help her, but I wasn't managing, and it all got too much. Most people had moved on, but I couldn't, so I got upset and overwhelmed. In the end, I was awful to my mam because she became so demanding and I didn't have a life. I felt like I was being forced to do things and people weren't listening to me."

"I was living alone and began to get panic attacks and sweating all the time. I was wandering around during the night in my pyjamas, knocking on neighbours doors because I was anxious and needed help." "My sister noticed I was losing weight and wasn't coping but nothing was done about it at first."

- Emergency accommodation could be entirely inappropriate.

"At first, I was put into a home where young people were dying."

"I was put in emergency accommodation and was locked in for weeks because I didn't have the number for the door."

The majority of people we spoke to were happy with where they currently lived, however two people told us that they weren't as they didn't feel listened to. One person was passionate about having his voice heard and on exploration was labelled "a complainer".

"I ask the staff to call my social worker to find another place to live but they don't do it."

- Some people with a learning disability can present themselves as less vulnerable than they are. This was evident when a lady whose speech was very articulate, with an amazing memory for facts but "Milkshake" (children's TV programme) and her new toothbrush with a rabbit head made her happy.

"I had my own place to live. I was pestered by kids and was pushed down the stairs by kids once and broke my hip. I'm not good at walking far now."

- Some people with a learning disability have their money controlled by the local authority. A few people complained about how this was managed:

"The council shut all my accounts and controls my money. I get an allowance now, but if I need anything, I have to ask them. A person at my day care goes to the mini bank and helps me get my money"

"My money is due every Monday but sometimes they forget to give it to me and then I have no money for my club or for snacks."

- We observed the impact of how important relationships are to everyone and that people with a learning disability often need help to make and sustain relationships. When this is done well, this makes such a positive difference to quality of life. This is demonstrated in the case study below.

Case Study

We are two 70-year-old parents of a 42 year old daughter with a rare genetic disorder which manifests itself in severe learning disabilities, autism, and poor physical mobility. We live in Redcar & Cleveland and are both now retired.
Our daughter lives close by but independently of us, in supported living with 24-hour care.
These are the things we now oversee:

- General oversight and continuing support.
- Her property and Finances as Deputies Jointly and Severally.
- Continued emotional support.
- When the level of care breaks down for any reason, we step in to cover any inconsistencies and respond to the situation.
- Support to access all medical services.
- Ensure she has a holiday and regular contact with siblings and extended family.
- Communication e.g., WhatsApp, to communicate with her support workers, and family and friends using her 'voice'.
- Promote person centered planning, review and updating where necessary.
- Access to community activities by highlighting events and facilitating her engagement.

We realised that as our daughter got older, she needed her independence and that we needed to retain our role as parents, whilst ensuring her care and development. Doing something about this took us through a plethora of emotions and concerns, taking us through a journey beginning with residential college, community residential care and eventually supported living. Our daughter was always at the fore front and centre of these developments. The whole family, geneticists and social services were also involved. We had a feeling that, as parents, our proactivity drove the process and was a continuous necessity.

The outcome of this process was long term supported living tenancy in her own flat with 24/7, one-to-one care.

We are happy with the outcome and do feel that it has improved things for our daughter, ourselves and family. We feel that she is in a good place, fulfilling her potential and happy that we have contributed to her enjoying a life of her own with a positive outlook for the future.

It was great to encounter professionals who were prepared to keep our daughter at the heart of decision making. However, it was challenging when some professionals let us down through poor decision making and by being driven by factors other than our daughters' best interests, in addition to poor communication and co-ordination between interested parties.

Parents need to be confident in the unique insight you have on your daughter/son. Acknowledge the contribution of 'professionals', whilst not minimizing the validity of yours as this is paramount to the outcome.

We feel that there should exist an independent and dedicated advocacy service other than statutory authorities which could be a present, personal and continuous service which could be alongside our daughter, speaking for her when family are no longer able to do so."

You need to be acknowledged and included as an equal stakeholder in the process and decision making.

"The process MUST ALWAYS be 'Person Centered' and continuous. This ensures a person's 'best interest' is not a one-off decision but a constant process as they live and grow. Those with severe learning difficulties have no less a right to recognition of life-long learning!"

Local Authority Position Statement

Below are position statements from each of our Local Authorities, outlining how they conform and are working to the Care Act 2014 and their consideration for NICE Guidelines (2018). NICE guidelines 'ensures that everyone with social care needs has access to services based on their needs, taking account of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation, and socio-economic status or other aspects of their identity.

NICE Guidelines (2108) state that 'In line with the Care Act 2014, local authorities must provide information about care and support services for people and their carers, including:

- the types of care and support available.
- how to access care and support, including eligibility criteria.
- how to get financial advice about care and support.
- local safeguarding procedures and how to raise safeguarding concerns or make a complaint.
- rights and entitlements to assessments and care and support services.
- personal budgets and all the options for taking a personal budget.
- information about care and support services is widely and publicly promoted'.

Middlesbrough

As part of our adult social care offer under the Care Act 2014, for the residents of Middlesbrough we are strengthening our prevention services for reablement, equipment and assistive technology. This will ensure that following a strength-based assessment, people are given the best opportunity to live as independently as possible in their own home, so that they can live the life that they want. For those whose needs are greater than can be supported by our prevention services alone, we will work together to look at the best support to meet their eligible needs.

Redcar and Cleveland

Redcar and Cleveland Borough Council review and implement a range of services that promote the wellbeing of our ageing population by supporting adults to live independently, preventing and delaying need and ensuing that an adult's environment supports their physical, mental and emotional needs whilst offering person centred care.

To meet these changing needs, Redcar and Cleveland Borough Council work with key strategic partners and a framework of providers to assess the current supported housing offer, and develop new schemes to meet any gaps identified in the market. In 2024, new supported schemes that will be delivered include a 71 bed extra care facility in Guisborough with an additional 12 bungalows attached; a care village in Kirkleatham offering supported housing including, bungalows, apartments and houses in a safe complex with carers on site and a 10 apartment dementia specialist scheme in Skelton.

Survey responses: full details

Full survey responses from the cared for person

We received the following number of responses from each area.

Middlesbrough	62	64%
Redcar and Cleveland	35	36%
Total	**97**	

We asked respondents to let us know who they lived with now.

	Middlesbrough	Redcar & Cleveland
Mother	29 (47%)	12 (34%)
Father	22 (35%)	11 (31%)
Brother	8 (13%)	0 (0%)
Sister	5 (8%)	0 (0%)
Grandma	0 (0%)	0 (0%)
Grandad	0 (0%)	0 (0%)
Other family member	1 (2%)	1 (3%)
Family friend	2 (3%)	1 (3%)
Carer	11 (18%)	5 (14%)
On my own	10 (16%)	10 (29%)
Other*	22 (35%)	14 (40%)
Answered	62	35
Skipped	0	0

* Responses to 'other' were from those who are living in supported accommodation.

We then asked them to list each thing they liked about living there.

Respondents were able to give their own answers and could list up to five things they liked. For ease of analysis, we grouped the responses into themes.

Activity/Theme	Middlesbrough	Redcar & Cleveland
Home/Environment/Feeling Safe/Peace & Quiet	69 (20%)	19 (15%)
Family/Friends/Relationships/Staff	62 (8%)	20 (16%)
Groups/Activities/Hobbies/Learning new things	54 (16%)	18 (14%)
Outdoors/Garden	31 (9%)	14 (11%)
Near shops and facilities	25 (7%)	17 (13%)
Having help	19 (6%)	8 (6%)
Food/eating out/pub	15 (5%)	5 (4%)
Work/doing jobs	14 (4%)	2 (2%)
Near family and friends	13 (4%)	8 (6%)
Pets/animals	13 (4%)	4 (3%)
Music/TV/Movies/Computer/Gaming	12 (3%)	7 (5%)
Good neighbours	10 (3%)	5 (4%)
Independence	4 (1%)	0 (0%)
Total number of responses	342	127
Answered	57	34
Skipped	5	1

We asked them what they needed help with now.

Activity	Middlesbrough	Redcar and Cleveland
Getting washed	24 (41%)	11 (34%)
Getting dressed	19 (32%)	5 (16%)
Making food and drinks	51 (86%)	22 (69%)
Going to the toilet	11 (19%)	5 (16%)
Washing clothes	49 (83%)	22 (69%)
Jobs in the house. e.g. Tidying up or cleaning	45 (76%)	16 (50%)
Shopping	47 (80%)	24 (75%)
Making phone calls	44 (74%)	21 (66%)
Going to appointments	54 (91%)	25 (78%)
Going to activities	52 (88%)	21 (66%)
Going to work	17 (29%)	10 (31%)
Seeing friends	47 (80%)	16 (50%)
Helping you with your money	52 (88%)	24 (75%)
Reading and writing	45 (76%)	22 (69%)
Physical activity	24 (41%)	12 (37%)
Keeping fit	35 (59%)	12 (37%)
Anything else* (please tell us what):	23 (39%)	15 (47%)
Answered	59	32
Skipped	3	3

‘I have no road sense, I need more exercise and I can't read or write, for example making sure I have fastened my seat belt in the car’.

‘My family helps with problems where I live. They are stepping in to help me find a better place to live in the future’.

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

Again, respondents were able to give their own answers and for ease of analysis these were sorted into themes.

Activity/Theme	Middlesbrough	Redcar & Cleveland
Groups/Activities/Hobbies/Learning new things	62 (37%)	36 (34%)
Family/Friends/Relationships	39 (23%)	35 (24%)
Outdoors/Garden	16 (10)%	6 (6%)
Holidays/day trips	15 (9%)	4 (4%)
Music/TV/Movies/Computer/Gaming	12 (7%)	14 (13%)
Pets/animals	8 (5%)	6 (6%)
Food/eating out/pub	7 (4%)	6 (6%)
Home/environment	6 (3%)	5 (5%)
Work/doing jobs	3 (2%)	4 (4%)
No of responses	168	106
Answered	60	33
Skipped	2	2

We asked respondents to let us know if they would like their own place to live.

	Middlesbrough	Redcar & Cleveland
Yes	16 (27%)	16 (46%)
No	19 (32%)	9 (26%)
Unsure	24 (41%)	10 (29%)
Answered	59	33
Skipped	3	2

We asked why they had given this answer

For those who did not want their own place to live was because they wanted to continue to live with their family and could not imagine living anywhere else.

"I want to stay with mam and dad".

"Likes being with family and refused to think about ever moving from the family home".

For those who said yes, these were mainly from people who had already moved into their own place where they had support.

"My advice to others would be to find somewhere safe you will like to live, where there are good friends and neighbours"

And if they did have their own place, would they like someone to live there with them.

	Middlesbrough	Redcar & Cleveland
Yes	24 (43%)	17 (52%)
No	7 (13%)	9 (27%)
Unsure	25 (45%)	7 (21%)
Answered	56	33
Skipped	6	2

If yes, who would that be?

We noticed in a lot of responses from the individual with a learning disability that their answers reflected their current situation or things that they had experience of. They found it difficult to make new suggestions where that experience had not existed.

This is an example of a response from an individual currently living at home.

"I would like my family to live with me. They take care of me".

Examples of different responses from individuals who are already in supported living, including things to consider.

"With friends who are like family and support workers to keep me safe".

"You will need somewhere where people are kind and you are looked after and safe. But it is good to have my own space so I wouldn't like someone living with me in my room".

"I like living in the building with people who I know, but I wouldn't like to share a room or facilities".

I like my current living arrangement. I was able to bring my cat with me. Although I live in a small flat on my own, I can also ask for help whenever I need it. Where I live, also has meeting places that I can join to socialise when I wish. I also come to regular day care which like very much.

However, other responses suggested that they would like their girlfriend/partner to live with them.

I would like my girlfriend to live with me. She lives in another room.

When I said yes, I don't mean just right after I got my own place, but I would like to share it with a woman that I'll fall in love with some day.

With my partner (I am on the lookout for someone).

We asked respondents if they would like to live somewhere close to where they live now.

	Middlesbrough	Redcar & Cleveland
Yes	39 (89%)	20 (80%)
No	5 (11%)	5 (20%)
Answered	44	25
Skipped	18	10

Tell us where you'd like to live:

As mentioned previously, respondents struggled to answer this question as it is difficult for them to answer something they have no experience of.

If I had been asked this question before I moved, I don't know what I would say.

The majority of respondents however wanted to live close to where they are now. The most important things for them were to be well connected with public transport, close to shops and near to their friends and family.

I like where I live now because everything is close by and I am familiar with everything.

We also asked if anyone had talked to them about where they might like to live in the future.

	Middlesbrough	Redcar and Cleveland
Yes	12 (25%)	11 (40%)
No	36 (75%)	17 (60%)
Answered	48	28
Skipped	14	7

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

	Middlesbrough	Redcar & Cleveland
I want to be involved in choosing where I live	24 (89%)	19 (90%)
Help to pack and move	25 (92%)	20 (95%)
Help to buy the things I need for my new place	25 (92%)	20 (95%)
Show me how to use things in my new place	25 (92%)	19 (90%)
Help me get to know my surroundings and my new neighbours	22 (81%)	17 (81%)
Someone I can contact who supports me with what I need	25 (92%)	19 (90%)
Have regular visitors	24 (89%)	16 (76%)
Take part in activities	27 (100%)	18 (86%)
Make new friends	23 (85%)	18 (85%)
Answered	27	21
Skipped	35	14

Is there anything else you would find helpful?

Other things that people would like help with were:

- Domestic tasks such as cooking, washing, ironing, locking the door.
- How they can volunteer and help others.
- Bereavement support
- Money and how to pay bills
- Healthy eating and diet
- Support with pets

Consistency is important - day care, routine and relationships that stay the same throughout all the necessary changes.

We also asked if they had been offered a Health Check, and if so, had they attended their appointment.

	Have you been offered a Health Check?		Did you attend your Health Check?	
	Middlesbrough	**Redcar & Cleveland**	**Middlesbrough**	**Redcar & Cleveland**
Yes	32 (55%)	21 (66%)	34 (58%)	18 (56%)
No	12 (21%)	3 (9%)	12 (20%)	4 (13%)
Unsure	14 (24%)	8 (25%)	13 (22%)	10 (31%)
Answered	58	32	59	32
Skipped	4	3	3	3

Why they didn't attend

For those who did not attend the majority of respondents said that they weren't aware that they were required to have one or had not received an invite for an annual health check appointment.

We also asked if they had a Health Plan?

	Middlesbrough	Redcar & Cleveland
Yes	22 (37%)	13 (42%)
No	13 (22%)	2 (6%)
Unsure	24 (41%)	16 (52%)
Answered	59	31
Skipped	3	4

And if so, what their Health Plan helps them to do?

	Middlesbrough	Redcar & Cleveland
General health/health prevention	14 (28%)	6 (17%)
Exercise/keeping fit	8 (16%)	6 (17%)
Helps to manage a health condition	8 (16%)	4 (11%)
Support with Medication	7 (14%)	7 (19%)
Weight management/healthy eating	6 (12%)	5 (14%)
Mental health care	4 (8%)	2 (6%)
Don't know	2 (4%)	2 (6%)
Health screening	1 (2%)	0 (0%)
Support with appointments	0 (0%)	4 (11%)
No of responses	50	36
Answered	22	16
Skipped	40	19

Other comments included:

I don't like my health action plan

My annual health check and health plan could be made a lot easier. It is all too complicated and communication could be better.

Do you want to tell us anything else?

Additional points that people wanted to tell us that provide us with examples to support the information in this report.

Long before mam died, she asked if I wanted to go into residential care but I said no. I felt I needed to help her because she wasn't managing by then. I did the shopping, got her pension, everything! But I wasn't managing and it all got too much. Most people had moved on, but I couldn't, so I got upset and overwhelmed. In the end I was a right cow to my mam and to my dog. Mam got dementia and became so demanding, I didn't have a life. I was being forced to do things and people were not listening to me. Mam was given a bell to call me whenever she wanted. She called me all day and all night. I took the bell from her and went to bed. She had tried to get up during the night and fell then had to go into hospital. After mam died. Moving house was never discussed with me. Most people knew before me that I was moving.

Full survey responses from carers

We asked respondents to let us know the relationship between them and the person they cared for.

	Middlesbrough	Redcar & Cleveland
Parent – Child	22	15
Married or domestic partnership		
Friend		
Other*	3	2
Brother	1	
Sister	1	1
Sister-in-law	1	
Grandparent		1
Answered	25	17
Skipped	0	0

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

Respondents each highlighted up to 5 things that worried them. We grouped the answers into themes for ease of analysis.

	Middlesbrough	Redcar & Cleveland
Quality of care/life & appropriate care	29 (23%)	16 (27%)
Who will look after them if something happens to me	23 (18%)	9 (15%)
Them developing health issues or changes in needs	20 (16%)	7 (12%)
They are safe/fear of being mistreated or abused	13 (10%)	8 (13%)
They have the help they need	11 (9%)	6 (10%)
Finance/Money management	7 (6%)	1 (2%)
Where they will live	6 (5%)	3 (5%)
Availability of groups & activities & services	5 (4%)	3 (5%)
Difficulties in looking after them as I get older or if my health deteriorates	4 (3%)	2 (3%)
Mental health	3 (3%)	2 (3%)
Respite	2 (2%)	2 (3%)
Mobility	2 (2%)	1 (2%)
No of responses	125	60
Answered	21	14
Skipped	4	3

We asked 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 then asked how they wanted to be involved.

	Do you know who to discuss future care with?		Have you discussed future options for the person you care for?		Do you want to be involved in the future planning of care arrangements?	
	Middlesbrough	Redcar & Cleveland	Middlesbrough	Redcar & Cleveland	Middlesbrough	Redcar & Cleveland
Yes	13 (54%)	10 (59%)	9 (36%)	11 (65%)	20 (87%)	16 (94%)
No	11 (46%)	7 (41%)	16 (64%)	6 (35%)	0	0
Unsure					3 (13%)	1 (6%)
Skipped	1				2	

How they want to be involved

Carers across South Tees told us that they wanted to be involved in all aspects of future care arrangements to ensure that the needs of the cared for person are fully met.

Carers would like to be involved in all discussions and have the ability to agree on the options available and that they can continue to do the activities they are currently engaged in.

Carers would like to be involved in the ongoing process of giving advice about what is best for the cared for person, their health and instructions of what their needs are.

I want to be involved in everything. As he gets older, I expect we will begin to talk about what he would like to do and what help he needs. I hope to get things in place and see him settled long before my husband and I can no longer provide for him.

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

	Middlesbrough	Redcar & Cleveland
17 or younger	3 (15%)	4 (27%)
18 – 20	0 (0%)	4 (27%)
21 – 29	2 (10%)	3 (20%)
30 – 39	6 (30%)	2 (13%)
40 – 49	7 (35%)	2 (13%)
50 – 59	1 (5%)	1 (7%)
60 or older	2 (10%)	3 (20%)
Skipped	5	2

There were varying answers to this question:

Many carers found that it was difficult to have this conversation with the cared for person. However, they agreed that conversations should take place as early as possible, so they have more time to plan.

Many expressed that they would do this for as long as they could but ultimately would depend on their own health and ability to provide the level of care. They were anxious about making these decisions too early as they told us that the level of care they are currently receiving would not be replicated in any other care environment.

I don't really know, because my son wouldn't understand and also you never know what's going to happen round the corner.

I am healthy and active now, so I am happy to care for him. So, it would depend at what age I may start to struggle caring for him.

It is never too early to talk about care arrangements - the current care arrangements we have in place happened by default, in an emergency, because there was nothing else and no plan in place.

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

	Middlesbrough	Redcar & Cleveland
Not aware of any services	12 (29%)	4 (13%)
Activities/Groups	8 (19%)	4 (13%)
Day Centres	4 (10%)	5 (16%)
Supported Living	6 (14%)	2 (6%)
Carers/PA	3 (7%)	5 (6%)
Social Care	4 (10%)	3 (9%)
Respite	2 (5%)	2 (6%)
GP/NHS	2 (5%)	2 (6%)
Care Home	1 (2%)	1 (3%)
Carers Organisations	0 (0%)	2 (6%)
Direct Payments	0 (0%)	1 (3%)
Mental Health Services	0 (0%)	1 (3%)
No of responses	42	32
Answered	14	12
Skipped	11	5

The responses highlighted that carers did not have knowledge of a diverse range of local services, especially those commissioned to support this community. Carers seemed to be more aware of services that provided more social activities for the person they cared for.

"With the cost of living high and to pay for the services is not enough to survive each month"

Activities that carers were aware of or engaged in:

The Shine Team
Teesside Ability Support Centre (TASC)
The Holiday Inn Group
Larchfield
Tin Hearts
Route 2
Earthbeat
Bridgehill
Redcar Cricket Club Sessions

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.

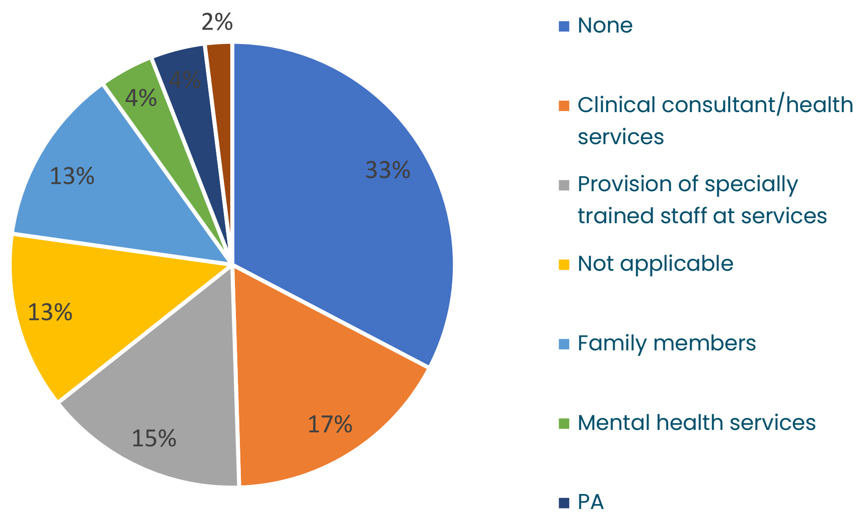
We have not split these numbers into local authority area as responses were almost identical for each geographical area.

NB: We did not receive as many answers for the second part of the question as we did for the first.

	Current Care	Continued Care
Day Centre	17 (17%)	12 (19%)
Me/Family	16 (16%)	2 (3%)
Carers/PA	14 (14%)	9 (14%)
Activities/Groups	10 (10%)	9 (14%)
None	10 (10%)	5 (8%)
NHS	9 (9%)	6 (10%)
Social Care	8 (8%)	10 (16%)
Financial Support	4 (4%)	0 (0%)
Respite	3 (3%)	5 (8%)
Direct Payment	3 (3%)	0 (0%)
Personal Independence Payment (PIP)	2 (2%)	1 (2%)
Mobility Care	2 (2%)	1 (1%)
Residential Care	1 (1%)	1 (1%)
Mental Health Services	1 (1%)	2 (3%)
No of responses	100	63
Answered	32	31
Skipped	10	11

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.

As responses to this question were quite low, we have grouped the two geographical areas together and themed the responses. This could possibly highlight a lack of awareness of support that is available or because this is their 'norm' they don't see the behaviours as challenging.



The majority of respondents (33%) told us that they do not receive adequate support to manage behaviours that challenge others in relation to the person they care for.

How it can be improved:

The majority of carers told us that it was important to understand the reasons for their behaviours and therefore prevent them from happening in the first place. They suggested this was only possible by getting to know and understand the person.

As a result of this improvements could be implemented at day centres by offering further training for staff focussing on challenging behaviours which would improve access to and experience of these services.

"When he lives independently, those that care for him will need to know him well".

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.

	Offered an Annual Health Check		Attend an Annual Health Check		Have a Health Action Plan	
	Middlesbrough	Redcar & Cleveland	Middlesbrough	Redcar & Cleveland	Middlesbrough	Redcar & Cleveland
Yes	18 (75%)	10 (58%)	16 (76%)	9 (64%)	5 (23%)	6 (40%)
No	5 (21%)	5 (29%)	4 (19%)	3 (21%)	13 (59%)	5 (33%)
Unsure	1 (4%)	2 (12%)	1 (5%)	2 (14%)	4 (18%)	4 (27%)
Skipped	1		4		3	2

Comments

Respondents told us that they were either not aware, not being offered at all or not been offered since Covid. Some suggested that the person they care for should have been offered one from a much younger age. There seems to be such a disparity of those offering this key aspect of identifying individual support needs.

An example of the barriers to getting an annual health check at the GP practice

"She is pre verbal with a cognition below two years. She is an anxiety refuser and will pull back when leaving the house. She cannot sit and wait. She will scream and strip off her clothes. She has to be medicated to see a dentist etc. I can get her in the car but not on demand. I can get her out of the car but not on demand. She goes nowhere, no day centres, cafes, walks, parks. The only place I can get her to is the respite centre, thirty years, thirty three nights a year, and she needs medication the night before to calm her enough for me to get her there. This still leaves a lot of nights for me alone".

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

	Middlesbrough	Redcar & Cleveland
Yes	15 (62%)	7 (47%)
No	0	3 (20%)
Unsure	9 (38%)	5 (33%)
Skipped	1	2

And if the respondent accessed local carers services, if they had a carers assessment and if they were registered as a carer at their GP Practice.

	Access Local Carers Service		Had a carers assessment		Registered as a carer at GP	
	Middlesbrough	Redcar & Cleveland	Middlesbrough	Redcar & Cleveland	Middlesbrough	Redcar & Cleveland
Yes	10 (40%)	9 (53%)	9 (36%)	8 (47%0	19 (76%)	13 (76%)
No	13 (52%)	6 (35%)	14 (56%)	7 (41%)	3 (12%)	3 (18%)
Skipped	2	2	2	2	3	1

Next steps for Healthwatch South Tees

- **These results will be shared with key support services to increase awareness of their offer to older carers.**
- **Raise awareness with key services regarding the number of respondents not registered with their GP Practice as a carer for this to be addressed.**
- **Utilise this information to provide insight with key local forums for action.**

Full survey responses from professionals

In total we received 56 responses from a wide range of professionals across South Tees, of these, 38 were from Middlesbrough and 18 from Redcar and Cleveland. The breakdown of organisations who provided responses is below.:

Middlesbrough Borough Council	19
Redcar & Cleveland Borough Council	7
Tees, Esk and Wear Valleys NHS Foundation Trust	9
South Tees Hospitals NHS Foundation Trust	3
Caring/Support Organisations	17
North East Commissioning Support	1

We asked respondents 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 (with 5 being the highest). We asked them to explain what it was that worked well, and the top 3 areas that would benefit from improvement.

Middlesbrough

Current process for moving older people with a learning disability into a new home	Rated 1-5	What works well	Top 3 areas that would benefit from improvement
Ongoing reviews to assess if people would like to move and the types of accommodation required. Annually the Learning Disability Teams hold an "away day" to plan future moves for all people known to services.	4	Have good understanding of the needs of people. Good understanding of accommodation needs. Have a good relationship with families/carers.	Suitable single accommodation. Affordable accommodation in areas where people are not being made more vulnerable. Carers/families belief that people are able to live away from the family home.
We have an established process following assessment at looking at all available accommodation alongside the wants/wishes of the person. We have up to date information around the availability of all types of accommodation and look monthly at planning for people waiting to move on and the compatibility where they may share with others. We do find identifying suitable accommodation for someone in an emergency, a challenge sometimes and now are experienced in working with Commissioning colleagues -	4	Monthly meetings with partners to look at availability and need. Careful transitions for people to enable us to properly consider compatibility. People having choice and control-us listening to their wishes for the future.	Emergency/crisis placements. Support providers experienced and skilled in dealing with most complex people. Variety and availability of respite care.

planning and developing bespoke accommodation for our most complex people.			
After thorough assessment within the multidisciplinary team (on my ward), if there is consensus that a patient/person needs to be moved to a new placement other than their original place of residence, then it is referred via the Trusted Assessor process to find the right place.	**3**	Multidisciplinary teamwork. That there is a single point to make such referrals.	Rarely get prompt discharges due to lack of places. Miscommunication between in-hospital and community teams about what is actually needed, or when things will happen. The government needs to invest into the NHS and social care.
This would be co-ordinated through social workers undertaking an assessment of need and then working with individuals /families around considered options .	**4**	Assessment framework in place. Learning disability social work team in place. Good understanding of the Care Act within Social Care.	More varied housing choices. Specialised provision for individuals with specific needs. Use of digital/technology within home environments.
This process is done through a social worker, parents and carers and input from ourselves.	**4**	Communication. Transition. Support the process.	Clear concise information sharing. Communication active. Transition
This process gets managed through the social workers and the staff team in their homes.	**3**	Communication. Visits. Keeping the process ongoing.	Communication. Staying positive. Maintaining links
Meeting with family/ carers/ social workers and the person, to make	**4**	Needs being met. Communication.	Communication with social workers.

the best decision to support their needs.		Support plans with carers/health professionals.	Social workers to be more attentive. Social needs being met.
Support totally with transformation to new home	**5**	Organising good to move. Settling in property. Accessing good services around area.	Bathroom accessibility. Stairlifts. Grab rails.
Don't currently have much input with this area. We may provide some person centred information about the individual.	**4**	Person centred information gathering. Visits to potential new homes. Chance to try out new accommodation beforehand.	
	1	Finding the right environment. Finding the right provider. Supporting the person through their journey.	Start the conversation earlier.
	3	Choices of provider in the area. Joint working with stakeholders. Engagement.	A service user forum with previous experience sharing. A central database. Sufficient local provision with adequate staffing.
	3	Building positive relationships. Understanding wants and needs.	Lack of choice in options available for people within their area. Discussions being started earlier in the process.

		Involvement of client throughout to ensue correct support.	Lack of robust providers with trained staff.
	2	Collaborative working within the local teams. Person centred. Carer involvement.	More choices for clients. For moves to happen more quickly as it can be a lengthy process.
	2	Multidisciplinary team meetings. Hearing what a person with LD would like. Supporting during journey/transition.	Better access to appropriate housing options. Lack of agencies to provide domiciliary care. Timescales needed to set up services are often very long.
	3	Coordination. Care packages. Multi agency working.	Options for appropriate settings for individuals - not just where there is a space. Environmental design - collaborative design. Communities rather than one building/segregation.
	3	Clients needs and wishes central to process. Collaborative working. Wellbeing of client is paramount.	Increased choices of environments. Working more closely. Increased advocacy to support transition.
	5	Communication. Working as a team.	Nothing.

		Agreement.	
	5	Communication with staff and social workers. Communication with client and social workers. Timescales.	None.
	3	Coproduction to achieve early outcomes.	Staffing from agencies. Communication. Finding suitable accommodation.
	3	Listening to everyone involved. Support through it all. Joint working with all the services involved.	Suitable housing. Forward planning. Carers involvement and users. No availability of choices and suitable care environment.
Overall Rating	**3**		

Please note that the professionals who attended the online workshop were not asked what the current process was for moving people with a learning disability, however they were asked to rate how well this process worked and highlight what worked well and areas for improvement.

Redcar and Cleveland

Current process for moving older people with a learning disability into a new home	Rated 1-5	What works well	Top 3 areas that would benefit from improvement
Best practice- multifaceted transition planning with family, carers, individual, advocates and professionals involved in care, however on occasions this is not always done collaboratively or professionals working closely with care providers whether in our clinical opinion can they are the right fit to meet the needs of the individual's which often leads to placement difficulties, breakdown and referrals into teams that could have been prevented. Causing upset to the individuals and their families.	**3**	Identification of changing needs and review. Evidence of partnership working.	Full collaboration across health and social care. Utilising intelligence from teams working into services. Out of area placements without full assessment.
Look at capacity, what the needs are, and what support is needed. How best to support the person and what is available in the accommodation. Look at the area to keep family included. What benefits are available? If needed, to court tenancy agreement, housing officer, case manager, accommodation management.	**4**	Teamwork. Information available. Person centred.	Timescale. Accommodation availability.
If a person lacks capacity to make a decisions regarding accommodation, then a best interests decisions is required to determine what is in that persons best interests with the persons	**5**	The referral process. Waiting lists/priority.	More supportive living schemes.

cycle of support who know that personal well.			
Encouraging families and adults to plan ahead. Lots of families are reluctant. No structured process.	**3**	Good planning.	More resources for families. More support for families to plan (carers support). More professionals talking about it.
	2	Meeting with social worker. Review PCP with users.	Communication. Whole system approach. Being able to respond to crisis.
	2	Meeting clients needs and wishes. Working with other agencies.	Limitation of suitable properties. Staffing issues for those that need support.
	3	Joint working between services. Involving the person and family in decisions. Transition planning.	Suitable accommodation to prevent going out of area. Robust providers to support complex cases. Improved communication when service users move into area.
	3	Relationships with supported housing providers. Self advocacy by service users.	More staffing provisions to support a successful transition to a new home.

		Shared experience of peers (other adults with LD).	Practice leaders to ensure staff follow care plans. Staff trained to provide the right support for the person moving.
	3	Professional involvement. Good needs record. Time to assess.	Communication of all parties involved. Appropriate support - as this can be a challenging time for the individual and family.
	3	Involving the person. Carer involvement. Professionals attempting to do best for the individual.	Communication between services and families. Earlier planning. More options for housing readily available.
	3	To work with various stakeholders and the service users family to plan well ahead.	Earlier planning. Improved resources. Current estates putting people in charge of the decisions for their future.
	2	Assessment of needs. Engagement with individuals. Viewing suitable environments.	Support for communities with additional needs. Cultural understanding of needs. Increasing capacity in the system.
	3	Services working together.	Engagement with families who have adults with LD living at

		Prioritising the individual's wants and needs. Ongoing support through transition.	home not linked into social worker to future proofing.
	3	Supporting the individual. Meeting with the social worker or CHC manager. Involving individual's family members.	More robust providers to be able to meet people's needs. Property availability with adaptions to meet needs.
	3	Collaborative working. Parent/carer involvement. Support.	Timings often too late. Availability to act quickly in crisis. Positives to moving out not promoted.
	3	Multi agency working. Person led.	Quicker response to proposed hours from LA. More detail in person need. Uniformed referral/enquiry method.
Overall rating	**3**		

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

Many professionals stated that there was limited support for older carers. They recognised that support is only given in a crisis situation and when this is coupled with carers not knowing who to contact for support, it has the following impact.

- There is a lack of regular assessments to identify changes in needs
- A lack of planning for future care.
- They are not receiving support that is available to them.
- Older carers not receiving relevant information in a way that they need it as they are not all digitally included.

"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"

"To plan and prepare for the future, to have some knowledge and to be educated on what is available for accommodation and support".

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

Adult social services
Advocacy services
Assistance with financial management
Bespoke services based on need including housing.
Continuing Health Care
Community LD Teams (health)
Day Service provision
Domiciliary care
Housing associations
Nursing
Occupational Therapy
Physiotherapy
Speech and Language Therapy
Supported living
TEWV LD services

We also asked what current services support a carer of an older person with a learning disability as they age.

Aapna Services	Healthwatch
Adult Social Care	Home Care Agencies
Advocacy Services	Inclusion North
Age UK Teesside	Independent Supported Living
Care Homes	Occupational Therapy
Carer support groups	Physiotherapy
Carers Together	Rapid Response
Community Nursing	Speech & Language Therapy
Community Teams	TEWV
Day Care Services	Voluntary Sector Services
GP & Primary Care Services	

We also asked the professionals to identify gaps in current service provision for older people with a learning disability when leaving home for the first time.

Advocacy
A service able to comment and complain without fear of reprisal
A service that challenges and befriends

Accommodation
Choice between shared living and solo living as well as residential
Choice of affordable accommodation
Choice of areas to move into
Choice of who to live with
Availability of accommodation choices and support staff
Correct pairing
Enough provision
Lack of appropriate accommodation/properties and resource
Lack of choices around accommodation/services available
Lack of domiciliary home care staff to support service user to integrate within the community
Lack of housing that is suitable depending on needs
Lack of properties in area of individual's localities
Lack of supported living homes and places
Limited spaces available

Lack of supportive living schemes with people of this age group
No specific provision for older people with learning disabilities, all are generic homes
Try before you move in to accommodation

Professional Support
Changes in professional supporting the client
Arising from carers who have not engaged with services
Not enough specialists
Not enough workers/carers
Also requiring support for physical needs/support
A Transitions role

Processes
Clear evidence of MCA and decision making processes
Clear transition planning – sometimes the process can be too long
Health Action Plans/Passports
Holistic transition, ensuring that everyone involved is supported and services are not pulled out too quickly to prevent potential crisis
Support for physical needs
Sharing of intelligence on placements, ensuring fit for the individual
Need for increased availability of supported living schemes
Varying transition timing

Liaising with the client to find out what their needs are rather than putting in one generic table where one size fits all
Person-centred plans need to be in place
Reassurance and trust need to be developed and carers included in planning

Communication
Information not made readily available for options
Lack of information give in the right way to support the persons understanding to enable the person to make the right choices so that it is a successful move
Consistency of service
Emergency and crisis response services

Services
Need more social support
Places to go for support
Pre learning on everyday living – how to pay bills, cooking meals, etc
Promoting independence
Proper care and support
Support to access community safely

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.

Processes
A holistic support package that keeps family members involved at all stages.
Access to independent advocacy
Agreements
Based on assessed needs
Be included in the move
Being listened to, valuing opinions and concerns
Bespoke
Choice & control of a number of different options.
Collaborative working between agencies
Community based therapies teams
Early transition that lasts as long as required
Effective support around the staff
Ensure that community is accessible
Ensure transfer is smooth. No issues
Framework of providers for care and complex needs
Genuine choice meeting individual needs, not fitting the person into a service that is available.
Identification of appropriate care provider who enables
Involvement of individuals
Joined up end to end support
Listening to the person
Meeting the individual’s aspirations and wishes
More information about local resources
More money
More options
Multi-faceted approach to placements
Person centred transition plan - based on a person’s needs
Proactive identification of need rather than reactive
Proactive physical needs/mobility/accessibility planning
Reasonable adjustments

Regular review of service specification/ design by commissioners to reflect changing demographics of placements
Social work team involvement
Involvement of statutory/VCS agencies for breadth of support required to ensure a successful transition
Support for carers
Weekly contact

Accommodation/Environment
Access to accommodation with peers in a variety of settings
Accommodation that meets the needs
An environment that is conducive towards supporting their needs
Appropriate housing
Arrange date for move
Arrange removals
Be a home from home with own personal items
Being in a location that is not too far from family home
Being with people that they are happy to live with
Choice of accommodation and where to live
Choice of housing and support teams
Decent standard of accommodation
Good outdoor space
I would like to see 'Shared Lives' provision increased for older people with LD. This provides more of a natural home environment
Identification of the right environment and in the right location
Integrated within the wider community
Living with who they want to live with
More options for accommodation
Personalisation of home environment to help provide reassurance and familiarity around personal possessions
Sleep overs
The right environment to meet the person's needs
Their preferred choice of where to live

Life skills
Being able to cook
Cooking lessons - freezing meals etc
Financial understanding - linked to capacity
Help with budgeting - training
Help with housekeeping - training
How to use a washing machine,
Knowing when to clean, change the bed, etc
Learning about community life - where to go, how to link in with local activities
Support with activities of daily living
Support with community access and participation
Support with learning new skills, accessing employment
Support with personal care
Teaching life skills
They can clean themselves - hygiene aware
They can cook
They know how to be safe inside their home
Training and support in daily living skills
Understanding how to shop - what to buy, how long it will last, etc

Support
24/7 if needed
Appropriate support and lead in
Getting the right individual support
Links to support staff
More 1:1 support
Ongoing support (not intrusive)
Ongoing training and support.
Other professionals in the client's bubble of support
Peer mentoring
Person centred care
Person led support that is not time limited

Staffing
Adequate staffing from agencies to enable support of the individual when there is staff sickness or holidays.
Appropriately trained staff
High staffing ratios.
More staff
Service users choose the staff to help support them
Staff with the correct skills and knowledge to support the person
Supportive and caring staff
The person choosing the staff who support them
Well trained staff

Quality of Life
Having a good quality of life
Community integration opportunities
Creative lifestyle plan
Day services
Fitness - encouraging exercise with carers participation
Good quality of life, promise for the future
Having a social life so not isolated
Meaningful activities for them to attend
Own independence
Support with mixing with peers of a same age
Time to carry out activities
Wellbeing

Relationships
Build up trust in friendships
Family
Family support
Family visits
Friends
Transparency and open relationships between the new support service and home /family

Health Care Requirements
Access to carers/nurses
Dementia awareness in all care staff
Access to doctors (both specialist and GPs)
Greater understanding of physical health care and learning disability needs
Health education and promotion
health support
Holistic health care
Right health care provision
Screening appointments kept

Mental Health Support
Mental health support and signposting
PBS approach
Timely referrals to mental health services

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.

Of those professionals who responded 17 said they were not informed if someone does not attend their annual health check and 28 said they were informed.

For those who said no the reasons were varied and it seems that whether they would know this or not depends on their role.

"This is not within our remit to check this as we are not the lead co-ordinator with an individual's care package . We may make enquiries and check with social work/community nurse colleagues to see if one has been completed and can check online social care records to see if one is recorded".

When asked if someone with a learning disability is always given a Health Action Plan, of those that responded 24 said they were not and 20 said they were.

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Reasons for a Health Action Plan not being offered are below.

"Some people are not aware of the yearly checks"

"Can vary from GP practices as to where this would sit within the GP practices priorities list around their Quality Assurance Framework targets. There is a financial payment issued to GP 's to complete one, albeit the duration for completing a health action plan and allocated available GP times can act as a potential barrier to them being completed"

"This is very hit-and-miss and relies on a proactive family knowing about the existence of a health action plan"

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.

Being Listened to
Care plan is current and implemented
Effective communication
Development of the Tees Valley Complex Care and Support Framework
Distract behaviours
DST reviews
Ensuring the client has a lot of Green in their lives (Lehmann chart)
Find out why/what triggered the behaviour
Following NAPPI UK (Lehmann chart)
Given Space
Good communication skills, understanding the individuals needs, working closely with carers to understand their knowledge around why the behaviours occur
Good practices
Group activities
Having Annual Reviews
Help to live independently
Keeping everyone in the support bubble aware of any changes positive and negative - keeping everyone in the loop
Knowing each individual and what their strengths are
Learning Disability Consultant attached to TWEV
Music or favourite comfort item to make person feel safe and relaxed
Pairing with the right carer to ensure they have the right support provided by the right carer who has knowledge and skills to help the client in a positive way
Partnership working between health and social care.
Person centredness
Planning with Individuals due to be discharged from hospital
Planning with people with forensic backgrounds
Planning with young people aged 16+
Pop up tent the person can go into when behaviour starts to change

Positive behaviour support plans from TEWV and also some specialists working for care providers.
Positive Behaviour Support training
Positive Behavioural Support Plans devised and delivered by specialist providers
Proactive dementia screening for people with a learning disability or Downs Syndrome
Proactive working with care providers to identify early indicators to presentation change
Providers on the complex care and support framework
Quality of Life assessment
Quality of life support from the community learning disabilities team.
Recording practices that are transparent and shared amongst key professionals
Reflective recordings and post analysis with key professionals so as to establish shared understanding and outcomes that help support interventions
Refocus residents
Ensure that risk assessments are current
Safe separate space in the accommodation where the person can go to and regulate their behaviour
The right to live and love, special relationships
Understanding
Using cards / pictures to communicate with people in a heightened state

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

People First who sub-contracts with other advocacy providers. Sub-contractors are:

- Middlesbrough and Stockton MIND
- Middlesbrough CAB
- DAD

Cloverleaf
Your Voice counts and also commission out of area Advocacy Providers.
Mind
Skills for people
Carers together
Age Concern
Middlesbrough First

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. To establish that all three experiences had considerable consistencies throughout was reinforcement of the observational and anecdotal feedback we receive. In addition, the feedback reinforced the NICE quality standards, established in 2018 for health and social care services, which are still very much relevant to the needs of those with learning disabilities.

There was a mixed response to how people felt they were currently involved in the planning of their own future care needs as they grow older. There was agreement that the process worked well when trained staff with good interpersonal and communication skills helped individuals and carers navigate the service pathways.

Some carers were apprehensive about discussing how their loved one would be supported when they are no longer able to care for them. For some it was the inevitable sadness of knowing that they would no longer be around for them, and for others it was concern over short term responses if they indicated they were struggling to care for their loved ones and needed support – that is they were concerned about them being taken into care sooner than they would want. Notwithstanding this natural concern, carers do want to be involved in planning for when they can no longer provide care for a 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.

Carers expectations and knowledge of health and social care services were mixed depending upon experience. The consensus opinion was good communication and targeted promotion of services available was needed to raise awareness.

All three groups of cared for, carers and professionals agreed 'good' looked like:

- Trained support to help individuals live an independent life:
- To help manage health, and emotional support for when they feel anxious about life.
- To help with household tasks and administrative tasks such as filling in forms, making appointments and managing finances.

- Social network: 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.

Those interviewed with a learning disability clearly expressed the need to maintain a continuity in their environment and a move into different accommodation would be more acceptable to them if it was in a neighbourhood they were familiar with and, where they could still easily maintain a relationship with their previous carers. The majority of our respondents hoped to live somewhere that offered them some degree of protection without imposing inappropriate constraints on their personal freedom. Unfortunately, the availability of such accommodation is described as being a problem, which is probably a reflection of the reduced availability of social housing in general, particularly for single people.

This is well recognised by both South Tees local authorities. However, assuming that the projected increase in the elderly population of the UK is also likely to be seen in those with a learning disability, then in the words of the UK Chief Medical Officer, It will be considerably easier to plan and build for this future if we do it now, rather than trying to retrofit at scale later.

Recommendations

- A range of suitable accommodation options is required, especially in crisis situations, to meet a variety of needs.
- Increased advocacy support for families to ensure they feel listened to at all stages of their care.
- Planning conversations need to start earlier with families including increased support for both carers and individuals during this transition as standard practice.
- Improve and increase person centered ongoing formal assessments and forward planning to reduce deteriorating physical and emotional health issues and arising emergency situations.
- Improved coordination between services in order to work better together to improve outcomes for all family members.
- There's a gap in services that support ageing carers. Carers support organisations need to target older carers to offer support.

- Increase training and development opportunities for volunteers and staff in order to improve retention.
- Increase awareness raising of support services, facilities and activities in the community for support workers to highlight additional engagement opportunities for these demographic groups.
- Increase support to develop life skills for adults with a learning disability in a variety of settings.
- Improved financial management systems which allows independence for individuals.

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 our investigation will be shared with the ICB, local commissioners, services providers, community and voluntary sector partners and the South Tees Health and Wellbeing Board as well as influencing future work programme priorities of Healthwatch South Tees.

Acknowledgements

Healthwatch South Tees would like to thank everyone who completed and returned a survey. The information you provided has been vital in the production of our report and the formulation of our recommendations.

We would also like to thank –

- Independent Voices
- Grenfell Club
- Aapna
- Middlesbrough First
- Larchfield Community
- 1st Enable
- Cumberland Resource Centre
- Erimus carers meeting

Appendix one: Demographics - Middlesbrough

Age category	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%
17 or younger						
18 – 20 years						
21 – 29 years	15	24.9%			10	40%
30 - 39 years	14	22.58%			5	20%
40 - 49 years	9	14.52%	2	8%	5	20%
50-59 years	15	24.19%	7	28%	3	12%
60 or older	8	12.9%	15	60%	2	8%
I don't want to say			1	4%		
Did not answer	1	1.61				

Gender	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%

Male	34	54.84%	8	32%	13	52%
Female	21	33.87%	17	68%	12	48%
Prefer not to say	1	1.61%				
Prefer to self-describe						
Did not respond	18	29.03%				

Are you currently…	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%
Single, never married	54	87.1%	1	4%	24	96%
Married or domestic partnership	2	3.23%	13	52%		
Divorced			1	4%		
Separated	1	1.61%	3	12%		
Widowed	1	1.61%	7	28%	1	4%
I don’t want to say	2	3.23%				
I don’t know						
Did not answer	2	3.23%				

Can you tell us if you have any physical or mental health conditions? (Please tick as many as you like)	Cared for person completing	%	Carers who completed the survey	%	The person they	%

	the survey themselves				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)	17	27.42%	9	36%	11	44%
Physical impairment or mobility issue such as: difficulty using your arms or using a wheelchair or crutches	8	12.9%	2	8%	4	!6%
Sensory loss such as: sight and hearing loss	9	14.52%	3	12%	3	12%
Mental health conditions or illnesses such as: anxiety, depression, and eating disorders	15	24.19%	3	12%	5	20%
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	39	62.9%			17	68%
Genetic conditions such as: Down syndrome and cystic fibrosis	14	22.58 %			7	28%
Prefer not to say	3	4.84%				
None			11	44%	1	4%
Other	3	4.84%	3	12%		
Did not answer	4	6.45%			1	4%

Ethnic background:	Cared for person completing the survey themselves	%	Carers who complet ed the survey	%	The person they care for	%

White						
White British	45	72.58%	21	84%	21	84%
Irish						
Other						
Asian / Asian British						
Indian	1	1.61%				
Pakistani	2	3.23%	2	8%	2	8%
Bangladeshi						
Any other Asian background			1	4%	1	4%
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	1	1.61%	1	4%		
I do not wish to disclose my ethnic origin	2	3.23%				
Other, please specify	3	4.84%				
Did not respond	8	12.9%			1	4%

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	14	22.58%	5	20%	7	28%
Christianity	15	24.19%	13	52%	11	44%
Buddhist						
Hindu						
Jewish						
Muslim	3	4.84%	2	8	1	4%
Sikh						
Other	1	1.61%	1	4%		
Prefer not to say	3	4.84%	2	8%	1	4%
I don't know	14	22.58%				
Did not respond	12	19.35%	2	8%	5	20%

Appendix two: Demographics – Redcar and Cleveland

Age category	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%
17 or younger					2	11.76%
18 – 20 years			1	5.88%	3	17.65%
21 – 29 years	4	11.43%	1	5.88%	4	23.53%
30 - 39 years	10	28.57%	1	5.88%	2	11.76%
40 - 49 years	4	11.43%	4	23.53%	2	11.76%
50-59 years	10	28.57%	4	23.53%	1	5.88%
60 or older	3	8.57%	4	23.53%	3	17.65%
I don't want to say			2	11.76%		
Did not answer	4	11.43%				

Gender	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%

Male	17	48.57%	4	17.65%	11	64.71%
Female	14	40%	12	70.59%	5	29.41%
Prefer not to say			2	11.75%	1	5.88%
Did not respond	4	11.43%				

Are you currently…	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%
Single, never married	26	74.29%	4	23.53%	14	82.35%
Married or domestic partnership	2	5.71%	9	52.94%		
Divorced			1	5.88%		
Separated						
Widowed	1	2.86%	1	5.88%	2	11.76%
I don’t want to say			2	11.76%	1	5.88%
I don’t know	2	5.71%				
Did not answer	4	11.43%				

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 comple ted the survey	%	The person they care for	%
Long-term standing illness or health condition such as: cancer,	8	22.86%	2	11.76%	8	47.06%

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)						
Physical impairment or mobility issue such as: difficulty using your arms or using a wheelchair or crutches	9	25.71%	1	5.88%	6	35.29%
Sensory loss such as: sight and hearing loss	9	25.71%	2	11.76%	3	17.65%
Mental health conditions or illnesses such as: anxiety, depression, and eating disorders	10	28.57%	4	23.53%	8	47.06%
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	18	51.43%	1	5.88%	11	64.71%
Genetic conditions such as: Down syndrome and cystic fibrosis	3	8.57%	1	5.88%	1	5.88%
Prefer not to say					2	11.76%
None			9	52.94 %	1	5.88%
Other	6	17.14%	2	11.76%	2	11.76%
Did not answer	4	11.43%				

Ethnic background:	Cared for person completing the survey themselves	%	Carers who completed the survey	Carer %	The person they care for	%
White						

White British	28	80%	15	88.24%	14	87.50%
Irish					1	6.25%
Other			1	5.88%		
Asian / Asian British						
Indian						
Pakistani						
Bangladeshi						
Any other Asian background						
Mixed						
White and Black Caribbean					1	6.25%
White and Black African						
White and Asian	1	2.86%				
Any other mixed background						
Black or Black British						
Caribbean						
African			1	5.88%		
Any other Black background						

Other ethnic group						
Chinese						
I do not wish to disclose my ethnic origin						
Other, please specify	1	2.86%				
Did not respond	5	14.28%			1	5.88%

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	9	25.71%	4	25%	6	40%
Christianity	2	5.71%	8	50%	5	33.33%
Buddhist						
Hindu	1	2.86%	1	6.25%	1	6.67%
Jewish						
Muslim						
Sikh						
Other	1	2.86%				
Prefer not to say	5	14.29%	3	18.75%	3	20%
I don't know	5	14.29%	3	18.75%	3	20%
Did not respond	12	34.29%	1	6.25%	2	11.76%

Healthwatch Middlesbrough & Healthwatch Redcar and Cleveland

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