

Learning Disability - The Carers' Voice.

Concerns and challenges

Joint report Healthwatch/Mencap's
Torbay Learning Disability Carers
Service

March
2021

Feedback report



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Introduction

Healthwatch Torbay is the independent consumer champion for people using local health and social care services in Torbay and South Devon. Healthwatch listens to what people like about services and what could be improved and shares those views with those who have the power to make change happen. In response to Mencap's queries about how to take forward carers' complaints about providers, the Learning Disability Commissioner suggested gathering the complaints by theme into a report. Mencap's Torbay Learning Disability Carers' Service initially invited their carers' group members to report on a number of continuing concerns about day care services for people they care for with learning disabilities and requested support from Healthwatch Torbay to independently gather, analyse and report on feedback received.

It quickly emerged that the responding Carers used the opportunity to share concerns about their wider experience of care support, including taking into account their own expertise from their lifetime of caring; the complexity of funding; and inadequate responses to feedback. This report is built around all those reported experiences.

The survey ran from mid-February to mid-March 2021. At this time Carers had provided 24/7 care for a long period of time, during the national lock-down put in place to suppress coronavirus transmission.

Context

Mencap Torbay Learning Disability Carers' service asked Healthwatch to carry out an independent analysis of these reported experiences. The analysis would aim to recommend steps to start the process of a systematic, long-term approach to quality improvement and learning for future provision.

A survey was used to provide anonymised reporting and was sent to the Mencap Torbay Learning Disability Carers' membership. The survey required the name of the service(s); a free text comment describing current experience and any suggestions offered for ways of working in the future.

As the aim of the survey was to understand the experiences of the family/unpaid carer, no comments were required from the cared for person. Not all comments were negative.

10 responders used the survey and provided 18 case studies. In addition, 1 letter and 1 telephone interview, provided 2 further cases. (12 individuals responded in total) As this survey was carried out under pandemic restrictions, face-to-face engagement was not possible.

In order to understand the context of comments extracted for this report, it is important to recognise that there is a nationally documented historic lack in formal capturing of the carer experience when planning service improvement for the person they care for (Healthwatch England, 2020. *Shifting the mindset*; National Audit Office, 2008. *Feeding back? Learning from complaints handling in health and social care*). As a result of this, carers are reluctant to make a case if they consider the care of their cared for person is at risk, or the carer considers nothing is consistently done to resolve the concern.

A brief literature search provided quality guidance for good practice in resolving the issues, of which the following were used to shape this report.

Overview: supporting adult carers | Quality standards (NICE, 2021; [Quality Standard 200](#))

- “This quality standard covers the provision of support for adults aged 18 or over who provide unpaid care for 1 or more people aged 16 or over with health and social care needs. It describes high-quality care in priority areas for improvement”
- “[Statement 2](#): Carers are supported to actively participate in decision making and care planning for the person they care for.”

Social care for adults aged 18-64 (*The Health Foundation, 2020*; [social care for adults aged 18-64](#))

- “...What often gets missed are the issues facing younger adults needing social care - people aged 18-64 with learning disabilities, mental health problems and other social needs - and the care they need to support their independence and wellbeing. This publication presents analysis of publicly available data to understand the needs of younger adults in the social care system, how they differ from those of older people, and how these needs are changing”

Good practice guidance for handling complaints concerning adults and children social care (*National Complaint Manager’s Group, 2016*; [good practice guidance](#))

- “These principles should be used as the minimum requirement for the handling of social care complaints and a source of good practice”

Complaints matter (*Care Quality Commission, 2014*; [complaints matter](#))

- “Complaints matter - to individuals, to health and social care services and to CQC. They matter for people using services, who deserve an explanation when things go wrong and want to know that steps have been taken to make it less likely to happen to anyone else”

Torbay Adult Social Care Local Account (*Torbay Council, 2020; [annual local account](#)*)

- makes a commitment to sharing ideas and learning and to implementing NICE ‘Supporting Adult Carers’ guidance

Strategy, policy and quality (*Torbay Carers’ Service, 2021; [strategy policy and quality](#)*)

- Triangle of care and commitment to carers (The Triangle of Care is a “Therapeutic Alliance” between the service user, professionals and carer that promotes safety, supports recovery, and sustains wellbeing.)
- “Respecting carers as expert partners in care”

Quality statements extracted from national guidance include:

- “There is wide variation in the way complaints are handled and much more could be done to encourage an open culture where concerns are welcomed and learned from. While most providers have complaints processes in place, people’s experiences of the systems are not consistently good” (Care Quality Commission, 2014).
- “Carers are supported to be actively involved in decision making and care planning if the person they care for agrees. Health and social care teams work closely with them and value their knowledge about the person they care for” (NICE, 2021).
- “When younger adults do access social care, quality and outcomes vary. The majority (89%) of younger adults using adult social care services report being satisfied with them. But there is evidence of poor-quality care, and national targets on supporting people with a learning disability or autism to live in the community have been repeatedly missed.” (The Health Foundation, 2020. social care for adults aged 18-64)

Findings

Summary of responses

Responses covered both Adult Social Care and Service providers. All carer survey responses have been analysed and grouped together in the bullet point summaries below according to the concerns described. These summaries are the views of those responding to the carer survey. A selection of illustrative verbatim responses to support these concerns are included in the appendix.

Adult social care

- Ineffective communication leading to lack of trust in the relationship between Adult Social Care and the Carer
- Lack of clarity about the invoicing process and in the explanation of charges and errors
- Insensitivity to the carers' stress and impact on the household, especially when the cared for person has challenging behaviour

Service provider

- No explicit co-production process, especially when inadequate day service accommodation requires change
- Inadequate recognition of the knowledge and experience of carers in the development of person-centred care for the cared for person

Complaints, concerns, and compliments process

For each of the five named organisations, where a negative sentiment for a named organisation had been expressed in the survey, their published (online) response to the concerns, complaints and compliments process (and the learning which resulted), were also checked. This looked for ease of complaints process identification and if service providers expressed how the findings were used for service improvement. We checked the ease of making complaints for carers with the 5 named organisations mentioned within the survey responses. We found no published evidence of how concerns and complaints were used to improve services.

Suggestions for the next lines of enquiry

The analysis of information provided by Mencap Torbay Learning Disability Carers show frustration and anxiety. Whilst the response was small in number, Healthwatch would like reassurance that this will not be ignored. A wider consultation, giving the opportunity for all Learning Disability carers to share their experience would enable a robust evidence base for future planning.

It is recognised that Adult Social Care is taking steps to improve services as identified within the current Adult Social Care Local Accounts ([torbay.gov.uk - adult social care annual local account 2019-20](https://www.torbay.gov.uk/adult-social-care-annual-local-account-2019-20)). With that in mind, Healthwatch emphasises that all services supporting the care of people with learning disabilities should be expected to have in place as standard:

- In line with Triangle of Care, Co-production of services to be the norm, as expressed by the Social Care Institute for Excellence (2013; [SCIE.org.uk - what is co-production](https://www.scie.org.uk/what-is-co-production))
 - *“Co-production is not just a word, it’s not just a concept, it is a meeting of minds coming together to find a shared solution. In practice, it involves people who use services being consulted, included and working together from the start to the end of any project that affects them”*
- The five principles for good practice in the handling of complaints, as endorsed by the Association of Directors of Adult Social Services (2016; [adass.org.uk - good practice guidance](https://www.adass.org.uk/good-practice-guidance))
 - *Principle one: ensure that the complaints process is accessible*
 - *Principle two: ensure that the complaints process is straightforward for service users and their representatives*
 - *Principle three: ensure that appropriate systems are in place to keep service users informed throughout the complaints process*
 - *Principle four: ensure that the complaints process is resolution focused*
 - *Principle five: ensure that quality assurance processes are in place to enable organisational learning and service improvement from complaints and customer feedback*

Response from Joanna Williams, Torbay Council, Director of Adult Social Services

“Many thanks to the people who have shared their experiences in this report, and to Healthwatch for compiling it. We are constantly seeking to improve the life of people with Learning Disabilities and their carers, and honest feedback is vital.

We will work with families, providers and Healthwatch to address the concerns identified, and continue to be committed to working together to find solutions.

The report covers the period of the pandemic, which has been a challenging time for all of us, but especially for people with caring responsibilities. As a result of the learning that has emerged from the response to CV19 we’re now working much more closely with Community and Voluntary sector partners. These relationships will be critical as we look to the future. Any future plans will, of course, be co-produced with people with learning disabilities and their carers and include an expectation of high-quality care.”

Mencap’s Torbay Learning Disability Carers Service response

“Thank you to Healthwatch for writing this report. It reflects the concerns, anxieties and in some cases the anger of the Carers we work with. Thank you also to the Carers who shared their wide experience and knowledge to bring this report to life.”

Appendix

Appendix 1. A selection of illustrative comments with negative sentiment (verbatim)

Adult social care:

Communication

- They did not listen, they refused to believe that a man with such needs could live in a normal home along with a young family & somewhere along the line it was suggested that we must be 'making it up'
- No dedicated care/social worker
- The social worker we were with did not seem interested in the fact that the manager of [...] had just said that he was 2:1 & that they would have to take on extra staff to keep them & him safe.
- Our lives were completely shattered never to be the same ever again, & the minute we raised a complaint ASC came after us with such venom that we never even knew what hit us. We live with the repercussions of this every single day.
- There is no one to support [...] to find paid work at the age of 29. April 2020, I rung social care and asked for a review of his needs ... “have you tried a charity shop for work?”
- I don't want to work with social care but that's all I've got to move forward with enablers

Funding

- They must have known at [...] that as self-employed care providers the hourly rate of pay was incorrect that Torbay were paying us. They have the opportunity to say something. But instead, they chose to believe that we were 'making it up'
- I feel that we are having more and more money taken off us - even though as a family we have less. Quite ruthless
- Can't answer some of the questions that arise. Not helpful especially as their letter when having a FAB assessment states, we are there to help.
- The financial cost to Carers is a very huge worry, getting to pension age that nobody is looking after us

Service providers:

Communication

- Poor communication, lack of involvement with other professionals [named organisation].
- Little forward planning for someone who wants to be independent staff entrenched in routine that suits them. Poor communication leads to confusion and only wanting to please staff ...I don't feel I have a voice anymore. I have tried but met with indifference. I am tired. Little has changed (supported living).
- In July 2019 [named organisation] decided not to renew their lease on rooms that they had been renting ...Staff were informed of this situation but were told not to tell the Parents/Carers ... the first we heard of this was when our sons' taxi driver informed us in November 2019 ... did not inform Parents/Carers until December 2020.

Funding

- Another negative is that I struggle to attract staff of the calibre I need because I am not allowed to pay the same rates of pay that these workers get for working with Devon direct payment recipients, or privately funded clients. It is ridiculous to expect highly skilled staff to work for less than an office cleaner. My son is also unable to access some opportunities because they would require 2:1 staffing, and social care do not provide this level of support. (Directly employed personal assistant).
- the cost for transport increased from £7 a day to £18 a day which ... has made it unaffordable. (Extract from a 3-page letter giving detailed impact experience following from a change of venue without full carer consultation in advance).

Knowledge and experience

- In the 18 months or so that we had agency staff before Covid hit, we never once had a review to talk about challenges and successes. Staff from agency were not experienced or qualified enough to be confident working with our son.
- We spent months ensuring our son's education and care plan was up to date and relevant before he left school at nineteen. We gave huge consideration to his learning goals and the outcomes we hoped to achieve. When he left school there was no provision at all in Torbay who were willing or able to support him in his learning goals.
- Very often people with a Learning Disability cannot cope with change very well, the [...] had been their home for fifteen years and now [named organisation] had moved them around three times in less than six months. ... moved their clients to the Boat Shed Totnes without consulting with Parents/carers ...

Appendix 2. Suggestions for future working (verbatim)

- To pay enhanced rates within a direct payment to enable Carers of severely disabled people to pay their staff a wage commensurate with their experience and skills and the responsibility they have supporting our son. It is unacceptable that I am losing staff because parents with direct payments from Devon social care get a considerably higher rate of pay for their PAs than Torbay gives. The rate of pay does not match even lower grade jobs like teaching assistants.
- Be more transparent. Have a dedicated care/social worker just to touch base every three/four months even if classed as stable.
- Adult social care needs to be listening to them [carers] to help shape a failing service.
- We need a Learning Disability team with some knowledge of what's out there, it seems to be that I have to find out the information to suggest to them. We should have a named person, that we can telephone if we have any issues, and I don't believe I should be brushed off by a receptionist at 219 700.
- When my daughter started everything was in Paignton which was why she loved it. Now its Totnes, Cockington and Paignton. Not so suitable. Needs more groups back in Paignton.
- We need a learning disability named person. It's all too generic do I have to know more than them to say what I need.
- None. The staff turnover is too great for agencies to provide high quality staff. Their staff are low paid, badly trained and generally lacking in continuity and experience.
- Be kind.
- To have examples and possible answers for the questions that might arise in assessment.
- Listen to her!
- Why can't we charge rent to our adult living with us?
- Devon has colleges for young people with profound and complex needs (funded by social care) which have the expectation of learning and personal development. Expectations of this cohort seem very low in Torbay. Give them a bit of sensory painting and they'll be happy between pad changes! There needs to be a 'hub' where young people can spend the day with their own PAs. At the moment, they leave the house in the morning and have nowhere to go in the cold and rain to have lunch, be toileted, or just relax in the warm if they are feeling poorly for example.

Appendix 3. A selection of illustrative comments with positive sentiment (verbatim)

- What an amazing team! They are so very helpful, considerate, and always puts the "cared for" person and their families first, any time day or night. Nothing is too much for them and they go above and beyond to help. (CLIP)
- Emma has really shone thought for us during this pandemic. Can't thank Caroline and Emma enough for reading and responding to my endless emails whilst in lockdown. Always being honest and not giving me lip service. Running Zoom coffee mornings and guest speaker evenings. Amazing! (Mencap Learning Disability Carers service Torbay).
- Pennie has made herself available as always during this pandemic. Always gives honest / experienced opinions (Carers Aid Torbay).

Appendix 4. Survey questions

Name of the first service you wish to tell us about

Please tell us more about your experiences with this service

Please tell us your suggestions for future ways of working with this service (optional)

Name of the second service you wish to tell us about

Please tell us more about your experience with this service

Please tell us your suggestions for future ways of working with this service (optional)

Please feel free to share any other information/comments about services that are important to you as a carer to someone with learning disability

If you would like to discuss anything with us further, then please provide us with your name and contact details (either phone number or email address) and we will follow up your request. Or telephone Healthwatch freephone on 08000 520 029. Thank you.

Contact us



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