

# What people said

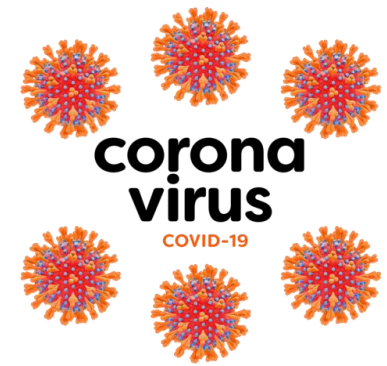
Speaking to people with a learning disability and autistic people in Kent



# Summary

- People we met had a lot to say about life in Kent, services and the difficulties they face
- There are lots of people who have experience and ideas who can support more positive changes across Kent and Medway
- Your advocacy organisations are providing lots of additional groups like book clubs and unpaid support for people who do not have access to support. Everyone across Kent and Medway should be aware of this support and its capacity.
- People had lots of experiences and expertise to help improve services, design services and communities
- People did not feel they knew or were told the facts about people in hospital from Kent and Medway and what the Council and health were doing for them

# Covid-19



- Some people told us about having their vaccination and gave us some examples of reasonable adjustments that were made e.g. nurse doing it at persons home due to needle anxiety
- Some people told us they had their second vaccine delayed and had to 'chase' people to get it
- Some people told us about how the day service or advocacy organisations had helped to make sure the person had meals or shopping
- People told us about being able to go back to volunteering and work at the end of the summer
- People told us about the impact Covid-19 had on their life from not being able to get shopping to feeling lonely, or examples where what gave them joy was no longer part of their life and they didn't know if it would be again

# Transport and community access



- People told us about the challenges they faced in the community using a wheelchair or walker
- We heard about the challenge of accessible buildings: No electric doors, people parked on pavements and more recently in one case stands being moved so people can distance in store but it now makes it difficult to get in and around the store
- We heard some examples of issues with accessibility and friends not being able to access public transport together
- We heard people wanted work together to improve transport
- We thought it would be great for Kent and Medway to use all this knowledge and support the development of accessibility audits for people with a learning disability and separately for autistic people across towns and transport

# Getting Involved

- People talked about being involved in interviewing staff for the council and other places
- People talked about the videos they had been involved in making and sharing
- People told us about accessing education and having opportunities to work
- People talked about the support they wanted to help develop to support people
- We heard about how some people no longer had support and not everyone had a good life
- People wanted to be involved and help make Kent and Medway a great place for people with a learning disability and autistic people to live. People had lots of ideas about how to do this.



# Good Support

- People told us what they thought good support was and where they saw that happening in their own lives
- We heard examples of people with lived experience trying to provide and develop new ways to support people through peer support, this was by luck and not design. We thought this sounded good and should be supported by Kent and Medway
- We heard about some of the struggles people have with making changes in their own lives and how difficult it can be to get the support they need to make it happen e.g. moving out of a care home into their own home, support when people feel low
- We heard about people who have a learning disability or autism having difficulties accessing mental health support. We heard examples of mental health teams not understanding the impact they have on people with a learning disability.



# Feeling safe in the community



- We heard stories from people about bullying and name calling in the community.
- We heard difficult stories that described abuse those people had experienced from a young age in hospitals, education, homes and institutions.
- We heard from people who felt worried about going back in to their community after the covid rules change.
- We heard that some self advocacy groups are working with the emergency services.
- We think it is important that Kent and Medway recognise and support people to report historic abuse and support commissioned partners to understand how to help people to do this and access follow up support.



# Support to have good mental health

- We heard stories from people about being passed from ‘pillar to post’ including passed between teams
- We heard about people not receiving personalised solutions to help them manage their mental health when they are anxious. E.g. crisis boxes filled with things that the person doesn’t enjoy or connect with
- We heard about people within crisis teams not connecting with people who had a learning disability or autistic people e.g. told not to let cat in her bedroom but that helps with her anxiety, it was her own home.
- We heard examples about the mental health crisis team that made us think they might need some extra training from experts by experience with a learning disability and autistic people to understand their impact on people and how they can help people better. E.g person wanting to hurt themselves, person being weighed and not knowing why – am I overweight? [www.local.gov.uk](http://www.local.gov.uk)



# Support to have good health



- We heard that people had health checks and hospital passports, but these were different in different places.
- People did not always get easy read information or support from health, often information was from self advocacy organisations and providers. Health services should be able to offer this to people.
- We saw how some self advocates used bracelets from a provider organisation, but we had not heard about those in our other conversations.
- When we talked about reasonable adjustments being flagged for all health partners people thought this sounded good and thought this should happen quickly.
- People had some great ideas about how to help people feel in control of their health e.g. having a printed copy from the GP of health check for the person to share with carers, having a document to complete with people before the health check to help remember what to talk about.



# Getting the help I need

- Some people didn't always understand the help they had, why they had it and what they needed to contribute financially e.g. we heard an example of paying for a social worker, possibly support worker, where they volunteer and the person didn't know they had a worker until they were asked to pay.
- Some people did not always find help from professionals useful to them, timely or strengths based.
- Some people talked about information that is on their health or social care record being inaccurate. This included records of 'behaviour' not including what was happening for the person at the time, places the person had been etc

# Building the Right Support



- People don't know if Kent and Medway has a lot of people in hospitals
- People don't know if people are getting out of hospitals
- People do not know if lots of people are going into hospitals
- People don't know about the plans to get people out of hospital, prevent people going in or check the quality of hospitals, to make sure people had Care and Treatment reviews (CTR/CETR)
- People told us Bemix are doing work about hospitals and report that work back to the Partnership Board
- We think it is important that the facts go to the Learning Disability Partnership Board and the Autism Partnership Board regularly as well as giving an annual report to people about Kent and Medway progress.

# Direct Questions to leaders



1. When Covid hit Aspens had to close and I was left with nothing how do we make sure this doesn't happen again? I couldn't access anything online when I was at home.
2. Money is always a problem. Why do we have to raise money and are not supported more through local government in partnership?

Contact Ross at Aspens to respond.

# Things people said



Its like walking into a forest in the dark and you don't know where your footing is

They expect that people can navigate their way around the system

I haven't been to any shops, I get anxious and worried

NHS fob you off, you ask them can you help me and they find a way to fob you off, they just pretend, they don't care at the end of the day they go home and are alright, I am depressed and searching for support (Drs)

When I had a CT Scan I don't get on with men so the Learning Disability Nurse arranged so I could have female only staff and that helped me lots

Re Mental Health 'they not taking an interest in me as a person'

I wanted to hurt myself, they didn't really speak to me, I thought they were supposed to help me. They didn't really help me.

The day services were shut down but I couldn't access online and couldn't do it at home

# What people want



More buses to go to other places

More driverless cars

Being able to choose, whatever your choice

Shut down all institutions and put all people into their own homes and own communities with the support they need

Make it easy for people to understand

Re health check: When you have needs like me, you should get a copy to take home to carers

More services that people need and want, more choice and options for living arrangements and good support

More groups to go to for making friends

I haven't been to any shops, I get anxious and worried

Make them listen and then act on that DO