

# Welcome



# Sean Nightingale

Speak Out Council Leader:  
Huntingdonshire and  
East Cambs



10:40



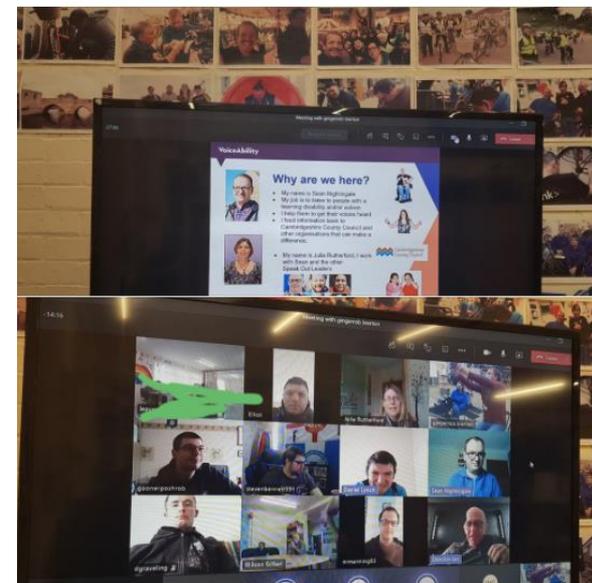
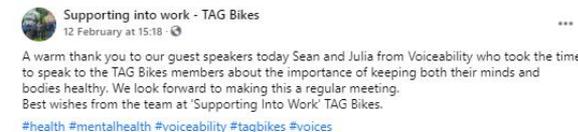
10:50



## What I've been doing?



- Consultations at Tag bikes, Shortsands and CATS (**C**ommunity **A**ction **T**oday in **S**t Ives)
- Starting to do drop ins at all 3 soon
- Huntingdon Health and Care Forum



# Health

## You said, we did



## You said, we did

In December we talked about health

### Annual health checks

We wanted:

- More people to be told about health checks because
  - A lot of people are not aware of them
  - Not all GPs are not inviting people for them

### Making a difference:

SEND, Cambridgeshire County Council have asked that health checks are discussed at all 14 years+ Annual Reviews.

We wanted more people to be told about health checks.  
Now they are included in SEND annual reviews



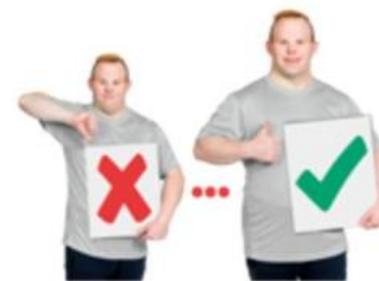
## Autism

**We wanted:** more help for people in their personal lives and around education, training and work

### Making a difference:

- A new health and social care service is being set up for people with autism across Cambridgeshire and Peterborough
- Speak Up Spectrum Leader, Elspeth has joined the autism strategy board for Cambridgeshire and Peterborough “bringing together services, creating an all age strategy, sharing best practice and starting to fill the gaps”.

**We wanted more help for autistic people**  
**The local authorities and health are working on a plan for everyone with autism in Cambridgeshire and Peterborough**



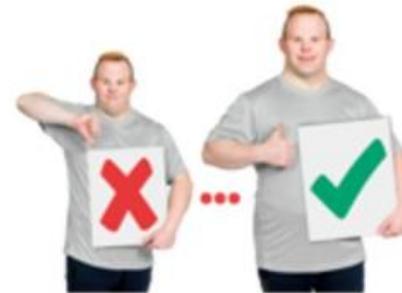
## Mental health

**We wanted:** more support for people to get the help they need for their mental health

### Making a difference:

Local Adult Community Mental Health services are submitting co-produced proposals for improving services to NHS England to make improvements from 2021/22

We wanted more support for people's mental health  
Community Mental Health services are co-producing a plan



We wanted more people,  
and health staff, to know  
about passports

They are now being  
included in Education and  
Health Care Plans

## Hospital and health passports

**We wanted:** more people, and health staff,  
need to know about passports and how to  
use them.

**Making a difference:** Children and Young People Health  
Services in Cambridgeshire and Peterborough NHS Trust have  
told us they plan to create health passports which can be  
included into young people's EHCPs.

HEALTH  
This is my  
**Hospital Passport**

If I have to go to hospital, this book needs to go with me  
It gives hospital staff important information about me  
It should be kept by my bed and a copy should be put in  
my bag.

Nothing and medical staff please look at my passport before you do  
any interventions with me

Name:

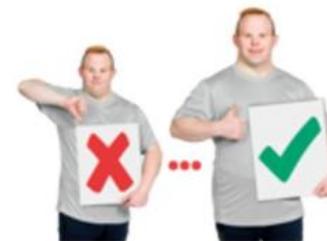
Date of birth:

Address:

Urgent appointment  
Independent supporter:

The Hospital Passport is based on original work by South West London Access Action  
Group and Education Partnership NHS Trust. **NHS**

The Hospital Passport was developed on:  Please date





Treat me well

We want people with a learning disability/autism to be treated well in hospital

We will keep doing this work and share it with the new Children's Hospital

## What else do we want in hospitals:

- More people and hospital staff to know about Learning disability specialist nurses
- People visiting hospitals to know how to ask for adjustments to be made (using a health passport and talking to the LD specialist nurse can help)
- More tracking for ceiling hoists in all hospitals so that people can feel safe
- Everyone to know how to complain if they don't get what they need

# Consultation

My life my future

Who did we talk to?



93 people  
did our  
survey!

**93 people have done our  
consultation but our charts here  
today are based on 74!**

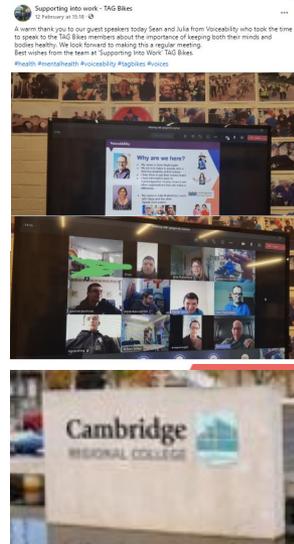
And we are still getting some surveys  
back in the post.



We met lots of people on line.

We met on line with people at

- Eddies
- Huntingdon Community Centre
- Shortsands, St Neots
- CATS, St Ives
- And young people at Cambridge Regional College in Huntingdon and Cambridge



Paper surveys and stamped envelopes went into activity packs



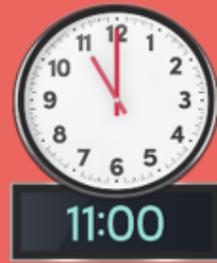
- Branching Out and Prospects Trust kindly sent out our paper surveys.
- We are waiting for some of these to come back.
- We will include them in our written report.





# Elspeth Jones

Speak Out Council Leader:  
Speak Up Spectrum



# Our lives in lockdown

- Last April and May we asked people how they were coping in lockdown
- We asked them the same things this year too





## Bad things about lockdown

We miss our family and friends

So many bad things it's hard to list them

My depression is getting worse

We are missing our usual activities

It is affecting my mental health

We are worried about returning to "normal"





## Great things about lockdown



- Creative activities
- Great things to do online
- Keeping in touch in our bubble

- Good support from staff
- More time for me
- Being on my own

- Better health – no colds, flu or COVID
- No migraines

- More time to ourselves and a quieter time
- Saving money

- Learning things
  - Gaining qualifications



# Ashley

Supported by Melanie, Thera



11:00



11:05

**My experience.....**





# Elspeth Jones

Speak Out Council Leader:

Speak Up Spectrum



11:05



11:15

## What would make it easier to go back to “normal”

- Transport and Travel
  - Help with travel costs so not having to use public transport in the first instance
  - Hard to leave mum, would prefer her to drive me and not take the bus
  - Not having too many people in my taxi
- School, college and day services
  - More IT/tablets for services so that people can start to join in again very soon
  - Having a "quiet room" to help me adjust to the noise with everyone going back at the same time

People would like help around public transport, IT and noise reduction!



## What I have been doing



- Speak Up Spectrum is back!
- Attended various All Age Autism Strategy meetings.
- First-hand experience of shielding and trying to get prescriptions delivered during whatever lockdown we are on now.
- Still trying to inject humour and sarcasm into team meetings.



(Smartie may appear in the background of my stream.  
Say hi!)

# Anne Hunt

Speak Out Council Leader:  
Fenland



11:15



11:30

## What I have been doing

- I am new to VoiceAbility
- I started as a Speak Out Leader for Fenland on 18 January 2021
- I have been lots of training including...
  - Induction with my Line Manager
  - Safeguarding Workshop
  - HR Workshop
- A consultation on zoom with Eddie's Day Centre in March
- Me and Neil had a zoom meeting with Pinpoint about preparing for adulthood





# Neil Adams

Speak Out Council Leader:  
Young People

## What has Neil been doing?

- **4 sessions with CRC students** in Cambridge and Huntingdon for our My Life, My Future Consultation
- **SEND Partnership Board** to tell them about the results of our Health Consultation
- **He talked to all the Special School Head Teachers** about Speak out Council and the work we do, when it is safe to do so we will go back into schools.



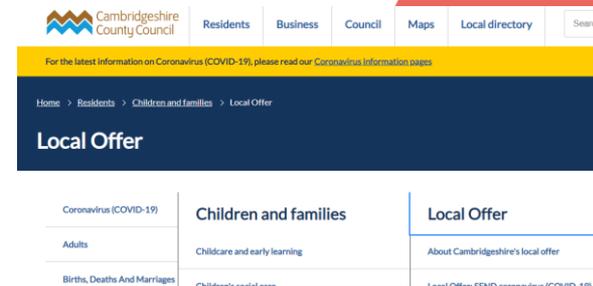
## What has Neil been doing?

- Neil and I listened to parents at the **PinPoint Preparing for Adulthood Connections event**. They want information about:
  - support for young people going to university
  - supporting young people to find a job
  - what happens when Education and Health Care Plans (EHCPs) finish at age 25
  - Benefits

Some parents would like us to:

- link with some new schools and colleges
- join the Speak out Group for people with more complex needs so that their young people's voices are heard.

- Neil and the other Speak Out Leaders gave **feedback to CCC about the Local Offer website** and how easy it is, or isn't to find information.



## Next steps for the young people's project

- **We are working with the Youth Action Boards** in Fenland and East Cambridgeshire to find out more, give them some training and support people with learning disabilities and/or autism to have a voice there.
- **We will be talking to Samuel Pepys students** in the next few weeks to hear what's happening in their lives at the moment.
- **We will be working with more special schools and colleges** over the summer term.
- **We will be supporting young people to have their say** about what the new Children's Hospital is like.





# The future

## What do young people want?



**How many young people did we speak to?**

We heard from **36** young people

**11 young people aged 14-25, and 25 people aged 19 – 25**

**36 young people told us about their**

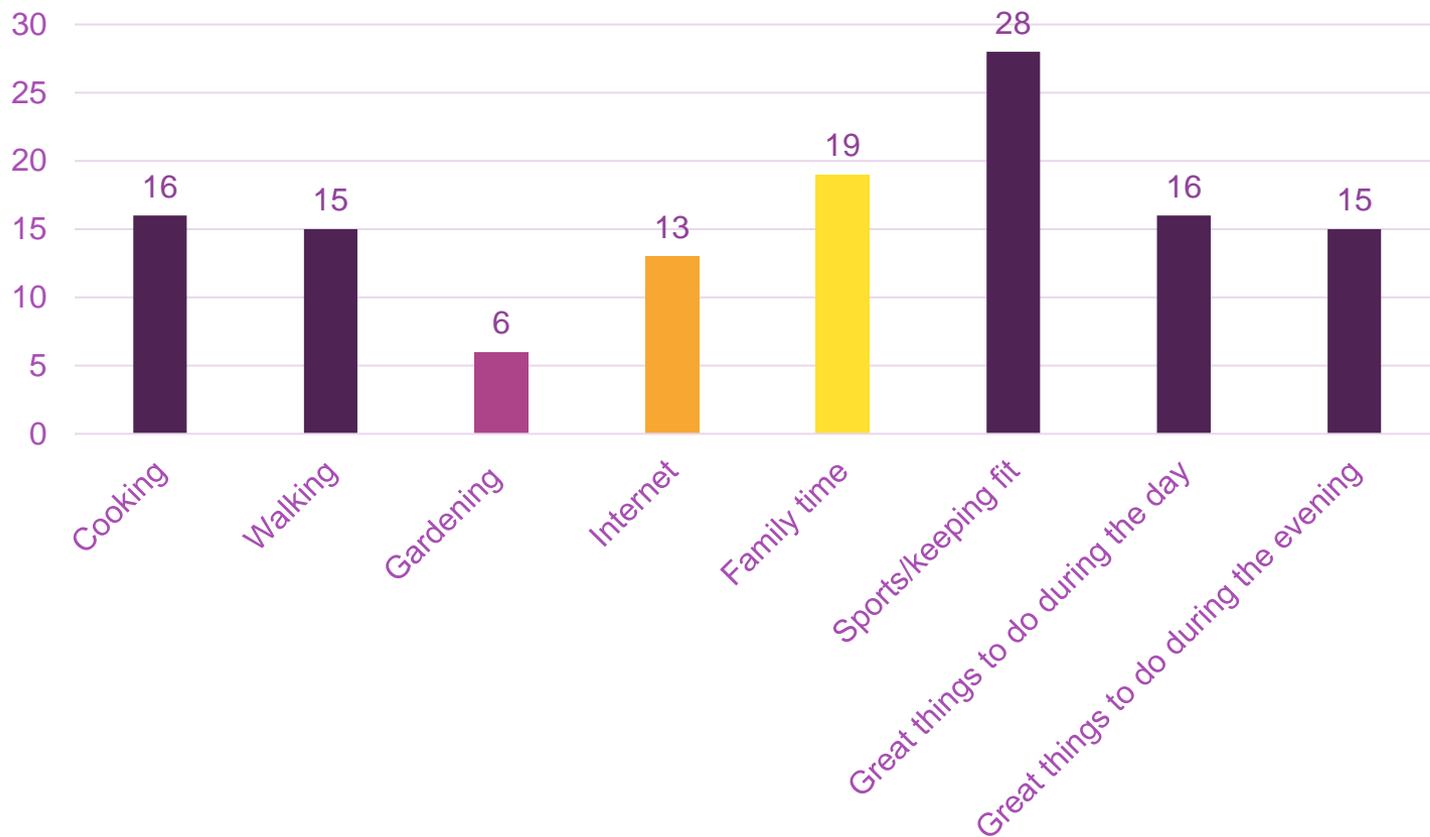
**We also spoke to 13 parents or carers who told us about their young people.**



## Activities we would like to do

Sport was really popular!

Activities we would like to keep doing or start doing.



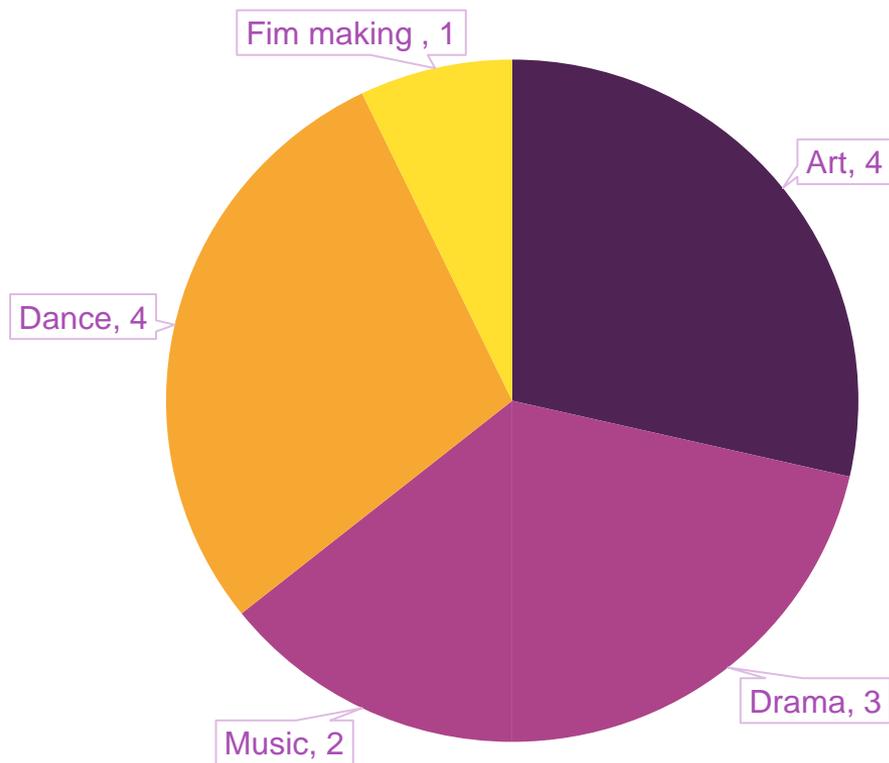
## Activities we would like to stop

Quite a few students weren't able to join online sessions as they did not have internet access.

Activities we would like to stop doing or don't enjoy



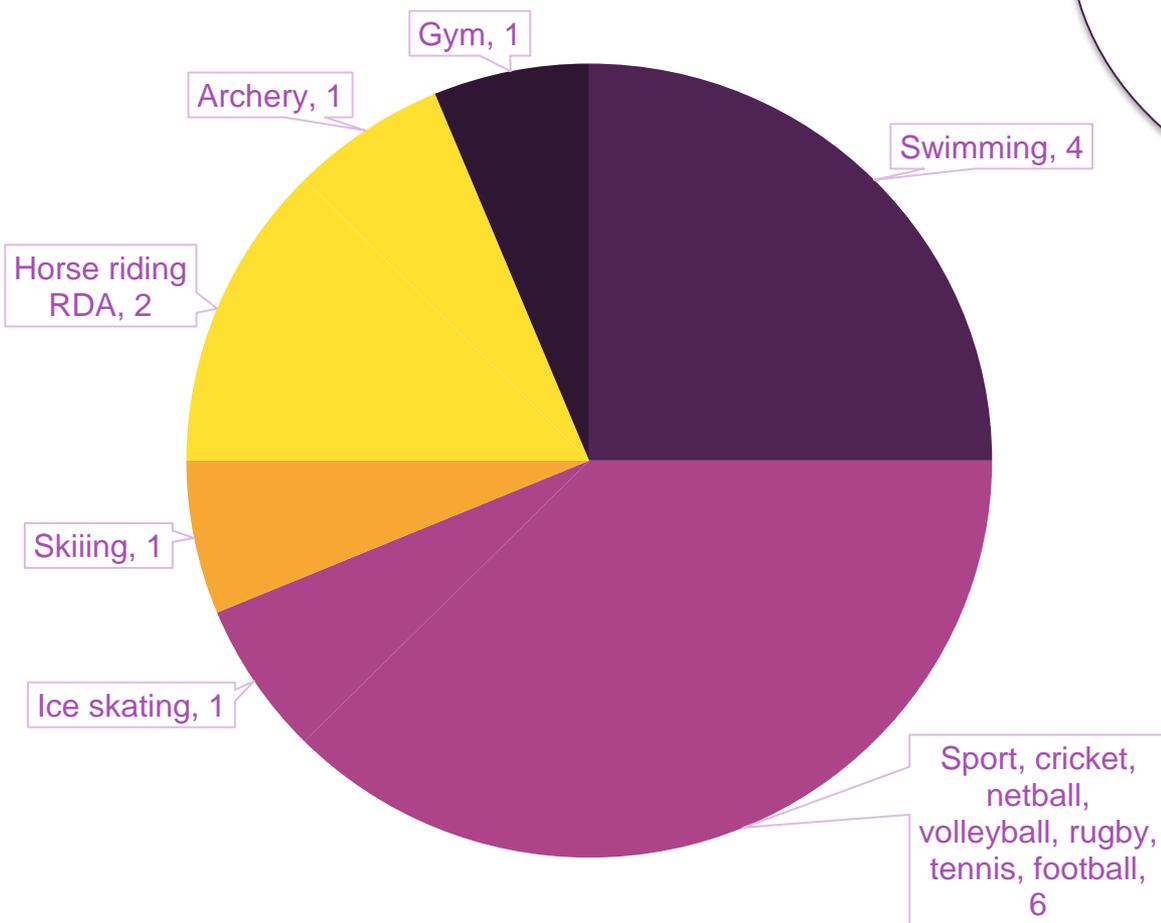
## New activities



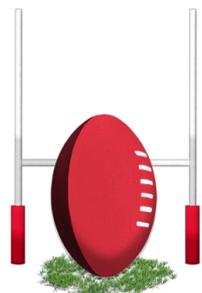
14 young people told us they'd like to do activities like art, drama, music and film making



## New activities

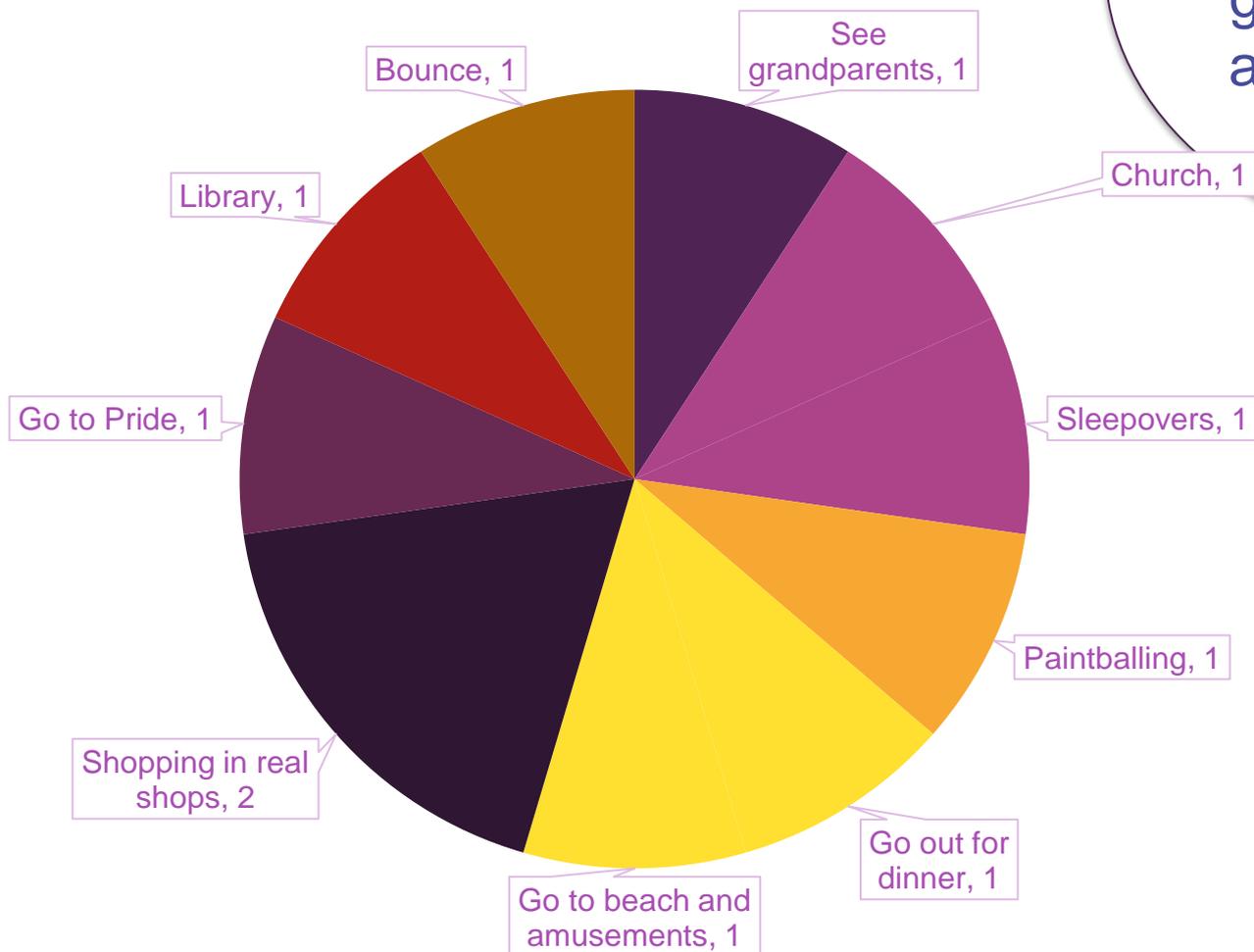


The young people we heard from are interested in lots of different sports!



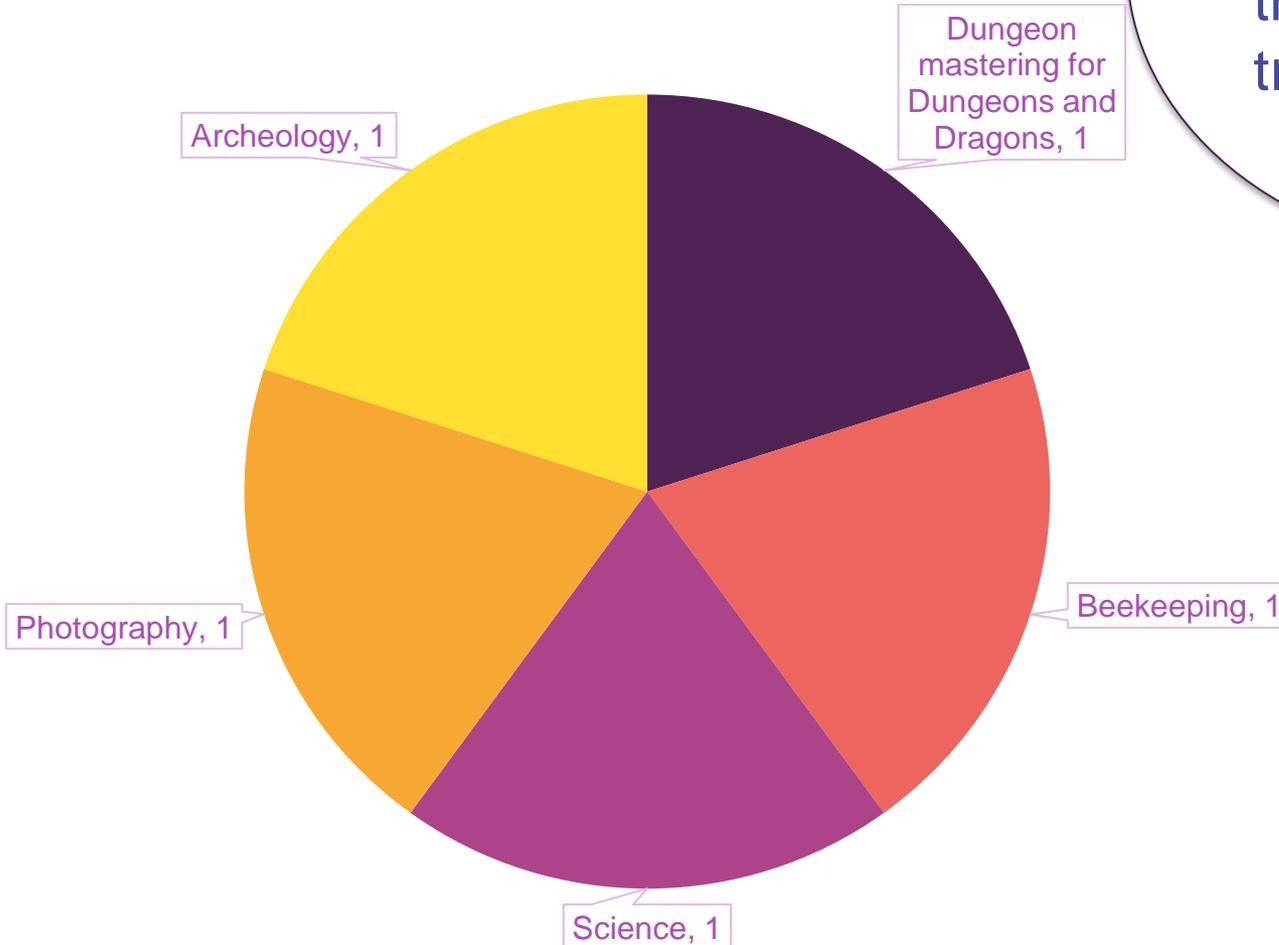
## New activities: out and about

Lots of people are looking forward to getting out and about again!

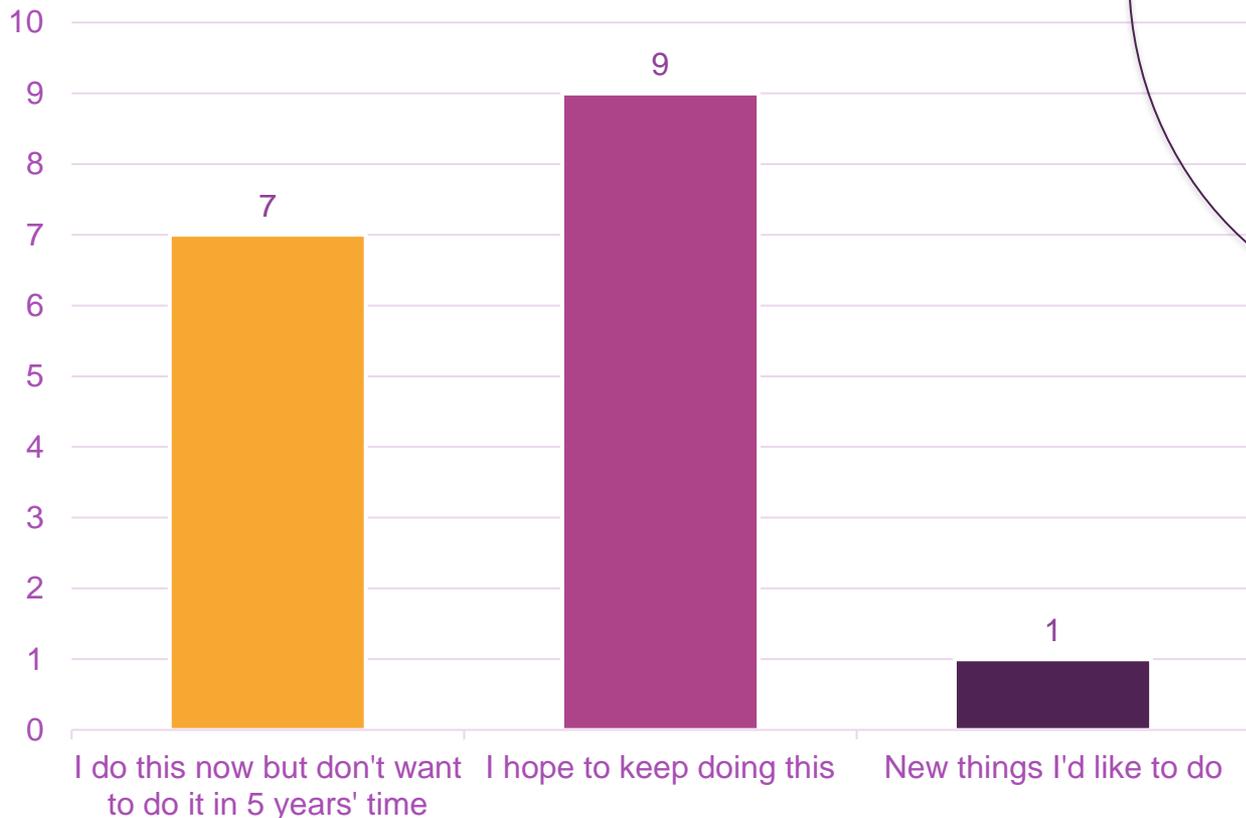


## New activities: hobbies

People told us about hobbies they would like to try.



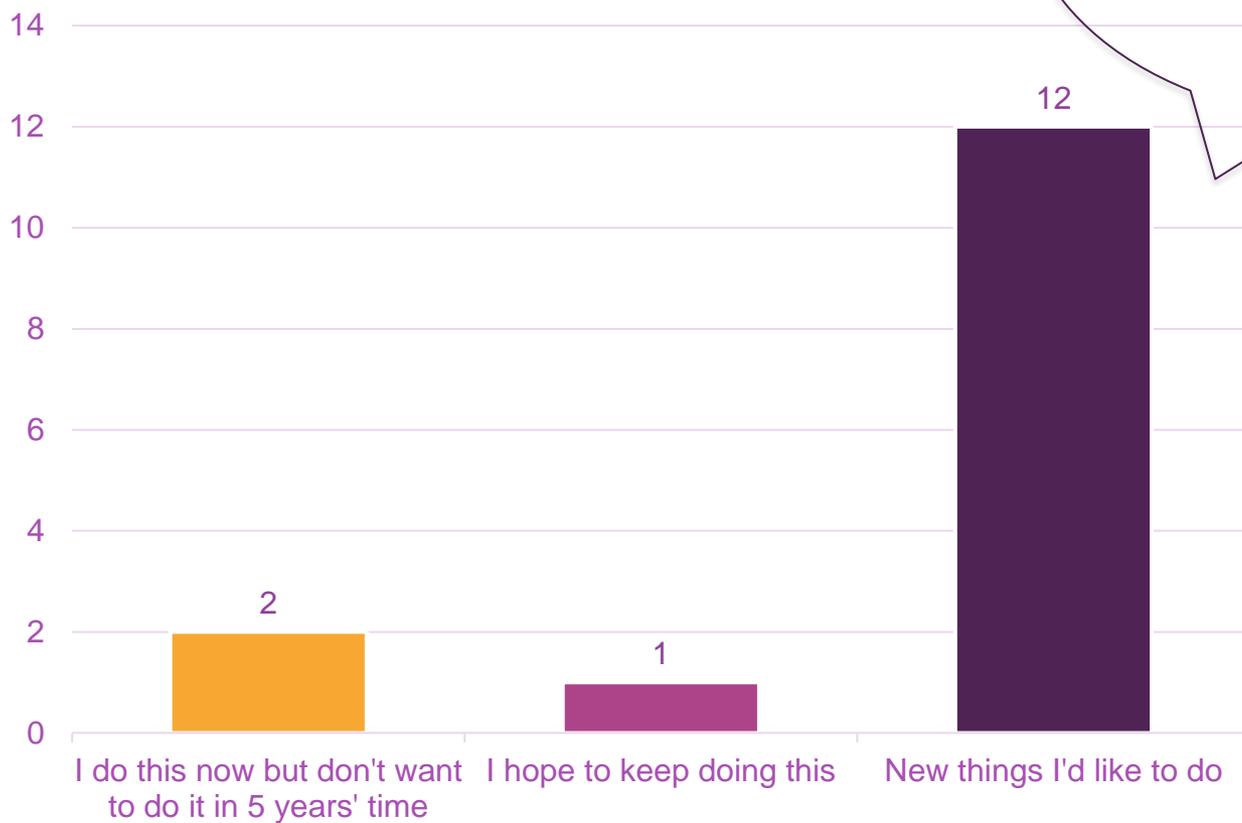
## Where we live: with family



Quite a few people are happy to stay living with their family but some people would like to move out in the future.



## Where we live: my own house or with my partner

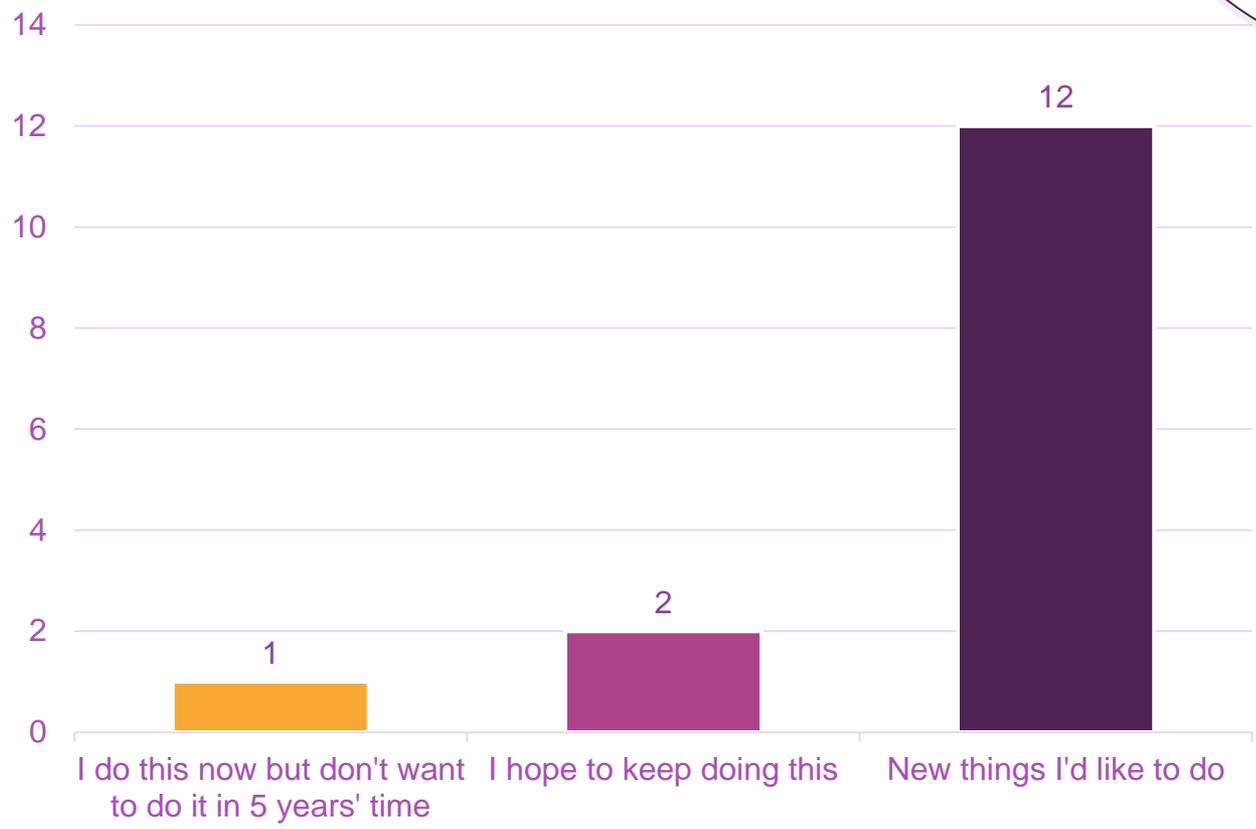


Lots of people want to have their own house.

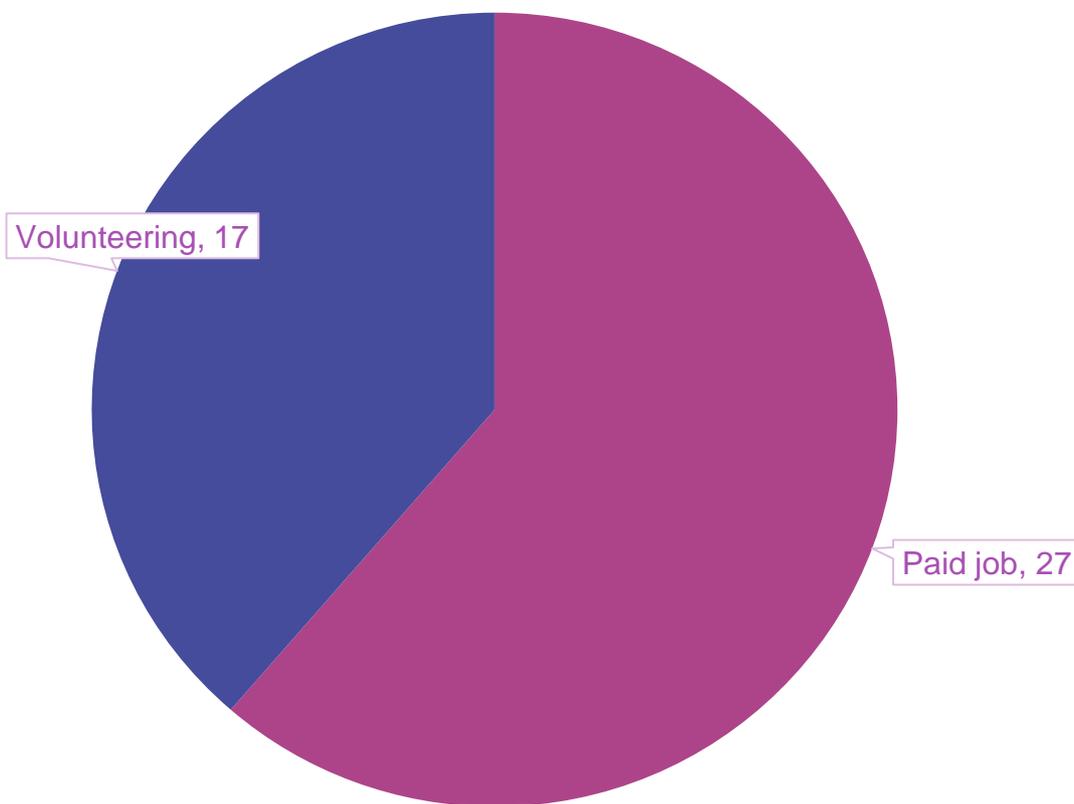


## Where we live: with friends

Lots of people want to live with friends!



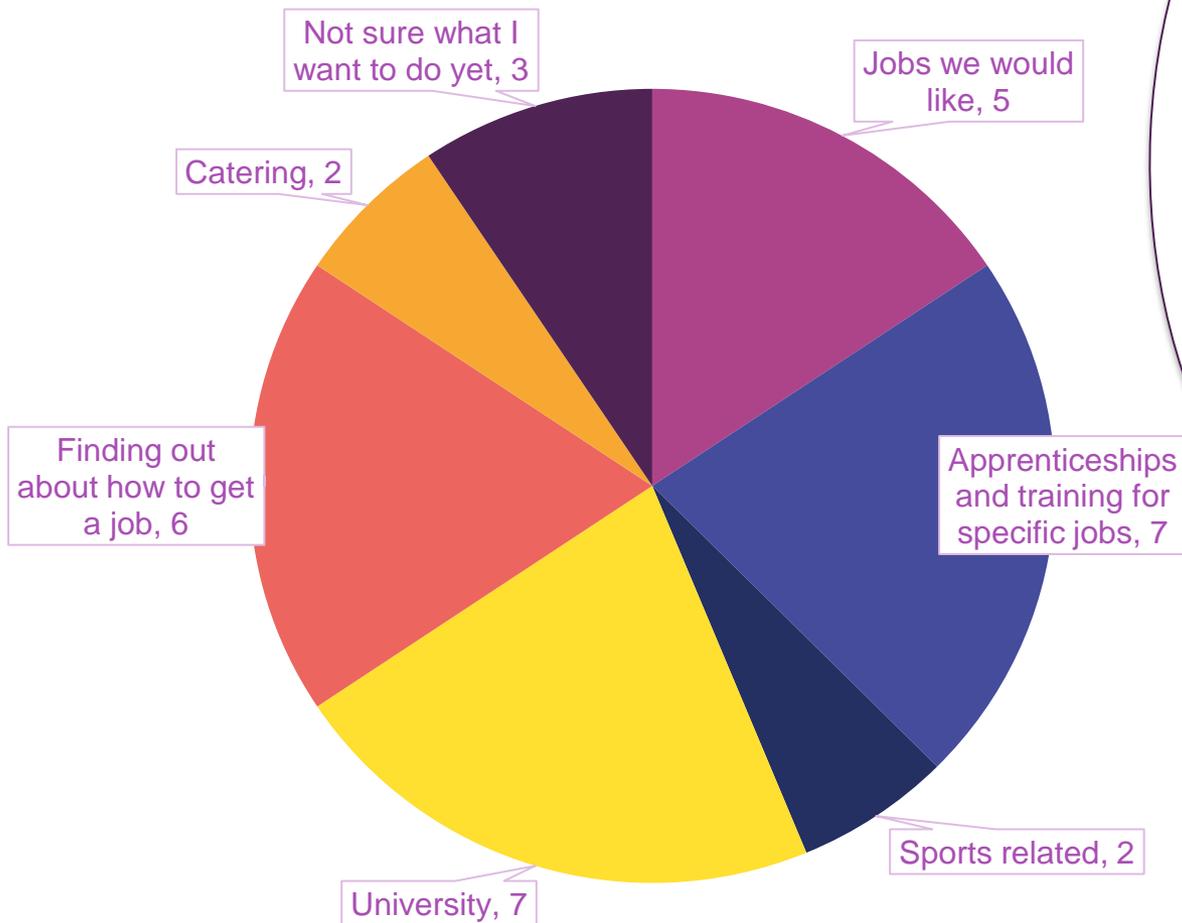
## Work and volunteering



Lots of people would like to find a paid job and/or do some volunteering.



## Training we would like to do something new



Some people know exactly:

- what they would like to do, and
- how to train for it

But quite a few people would like more information about how to find work



## What we would like to learn and work as in the future

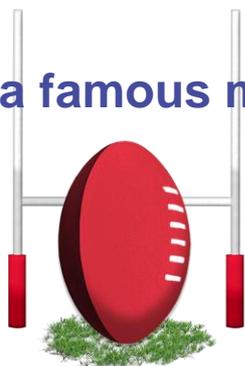
Nursing apprenticeship

Designing cars or games



Cafe

Be a famous musician



Bricklaying training.

Being a Support Worker



Online business, work for google

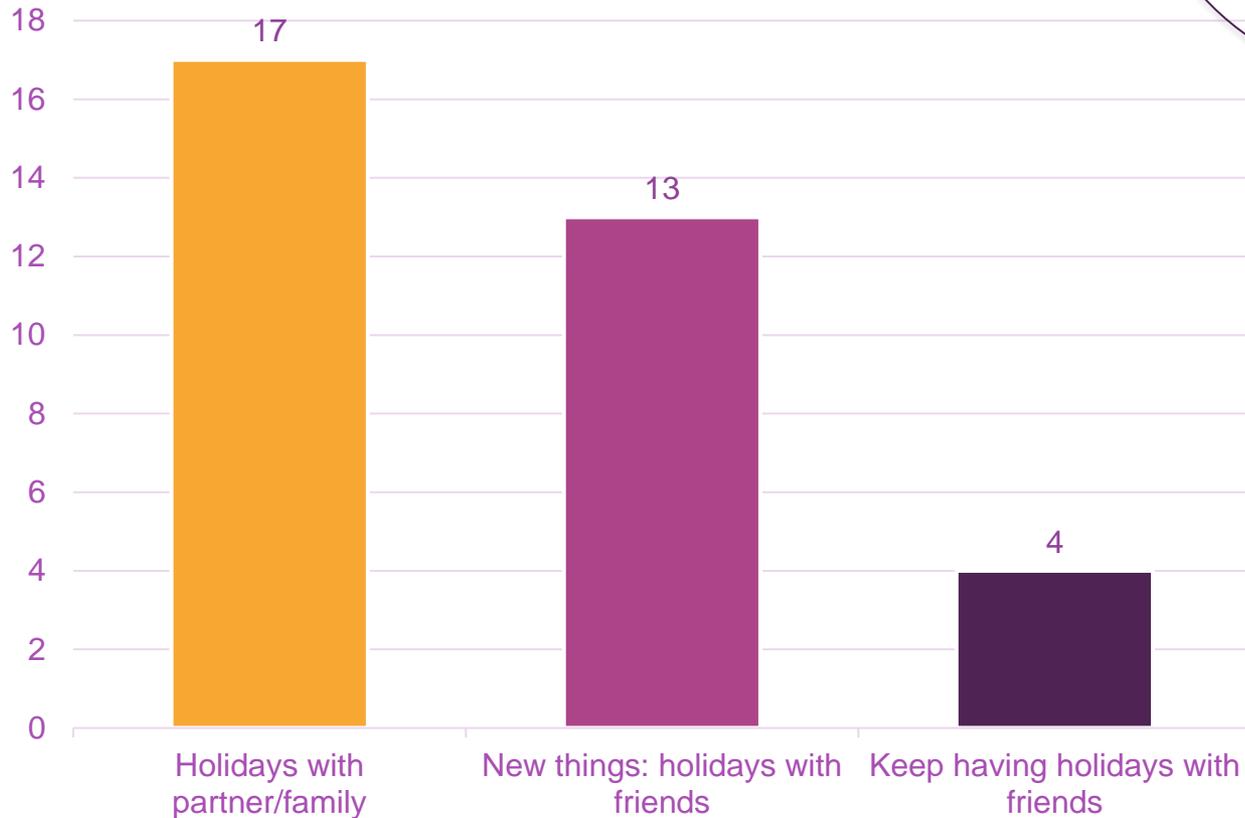
I need skills training around getting a job! Job interviews, CV



Singer, Vet, work in a zoo, work in a library



## Holidays



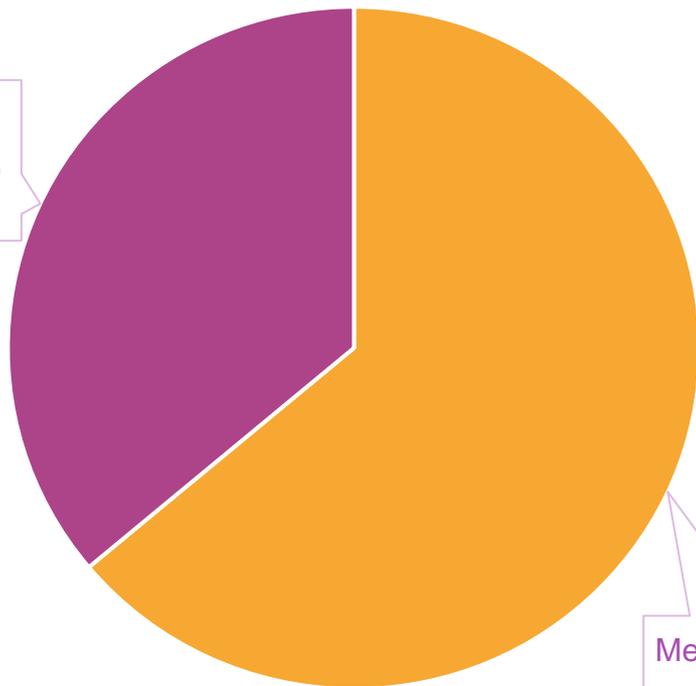
Lots of people would like to go on holiday with their friends and also their families.



## Friendships and relationships

Lots of people would like to meet new friends or find a girlfriend or boyfriend. We told people about Safe Soulmate

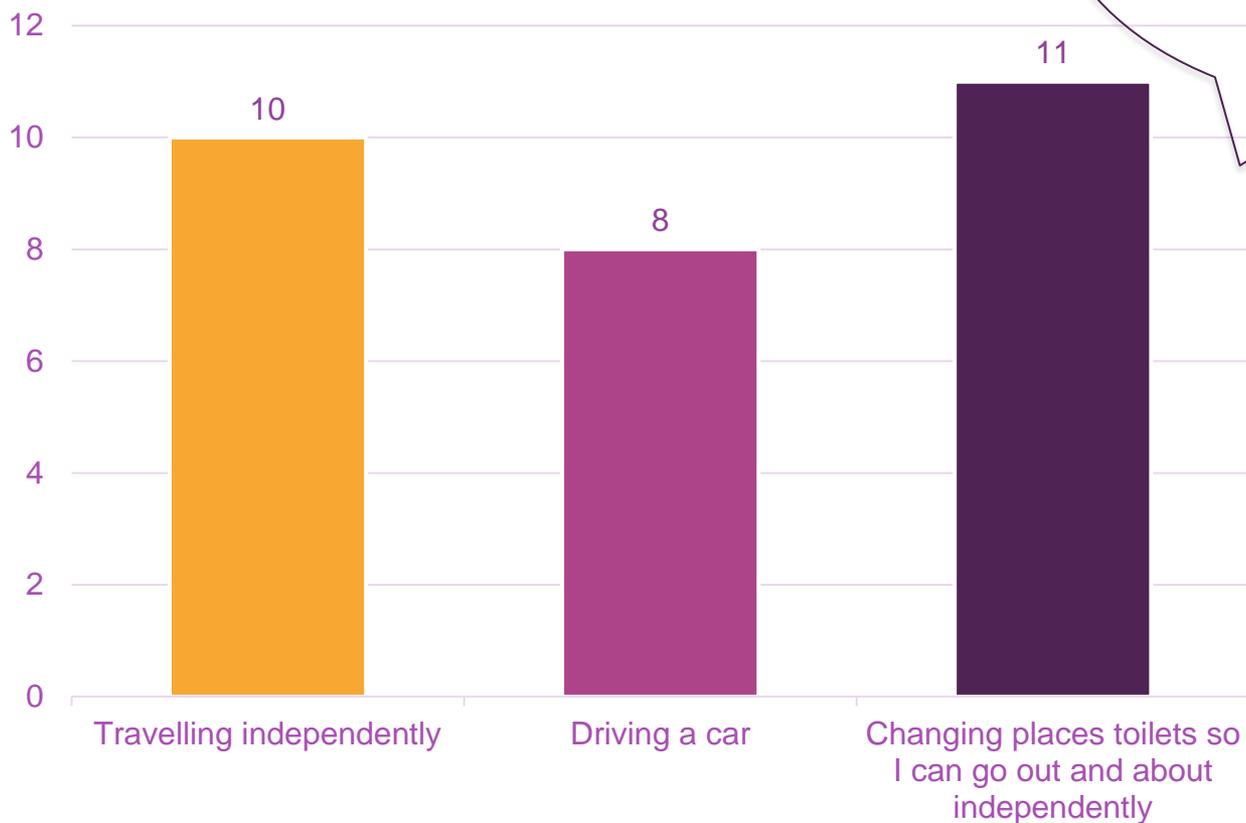
Have a girlfriend/boyfriend, 13



Meet new people, 23



## Travel



Being able to travel independently is important to people.



## Other things we'd like to do in the future

Unsure as to what I want to do when I'm older but I would like to make a difference in the community and support others around me.

Hopefully tie the knot with my darling girl and get married.

Pursue a relationship, make a difference through my social enterprise work, gain confidence, go to Japan, make videos with my sister, create a story based work like a game or a movie or a comic, find opportunities to be creative

To get married and win lottery (move to Spain and holidays) learn more about science/solar system. Learn maths. Holidays with day service.

## Support and information we need

**Alternative learning methods for large amounts of information**

**Life and independence skills**

**Work experience in hospitable places that universities will find attractive**

**Support to go out in the evenings inc transport**

**I would like some support in meetings**

**Physical support to be living independently, research into M.E./C.F.S. so that my health outcomes improve, coping mechanisms for anxiety, a therapist who is skilled in working with autistic people, building support networks.**

People would like all sorts of support, including work experience, support to live independently, support in meetings, going out in the evenings and building their own support networks.





## Parents and carers thoughts

Me and Neil listened to parents at the **PinPoint Preparing for Adulthood Connections event.**

- They are worried about support for their young people when they **move on to university**
- They would like to know more about **supporting young people to find a job**
- They would like more information about what happens when **EHCPs finish at age 25** and support to plan for their young person's future.
- They are worried about their **young people's mental health and making friends.**
- They would like clearer information about **benefits.**
- Some parents would like Speak Out Council to link with some **new schools and colleges.**
- Some parents would also like to **join the Speak out Group for people with more complex needs** so that their young people's voices are heard.

# Bill Jones

Speak Out Council Leader:  
Cambridge City and  
South Cambridgeshire



11:50



12:05

## Some examples of what I've been doing?

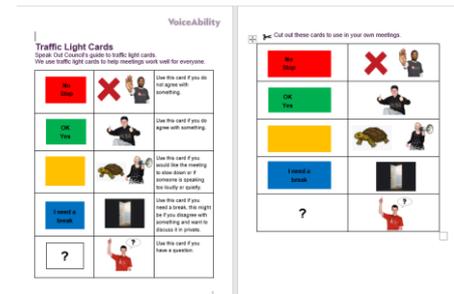
- Continued to be involved with Connect2Work sessions
- Now actively going to Speak Up Spectrum meetings again
- Checked out some Mental Health and Disability Social Care letters
- Have restarted my South Cambs drop ins which are being done virtually
- Created a guide for chairing meetings



## Some examples of what I've been doing?



- I helped with making new communication cards
- Also did a guide for the traffic lights cards
- I also did Email Training
- Learning Makaton through Safe Soulmates



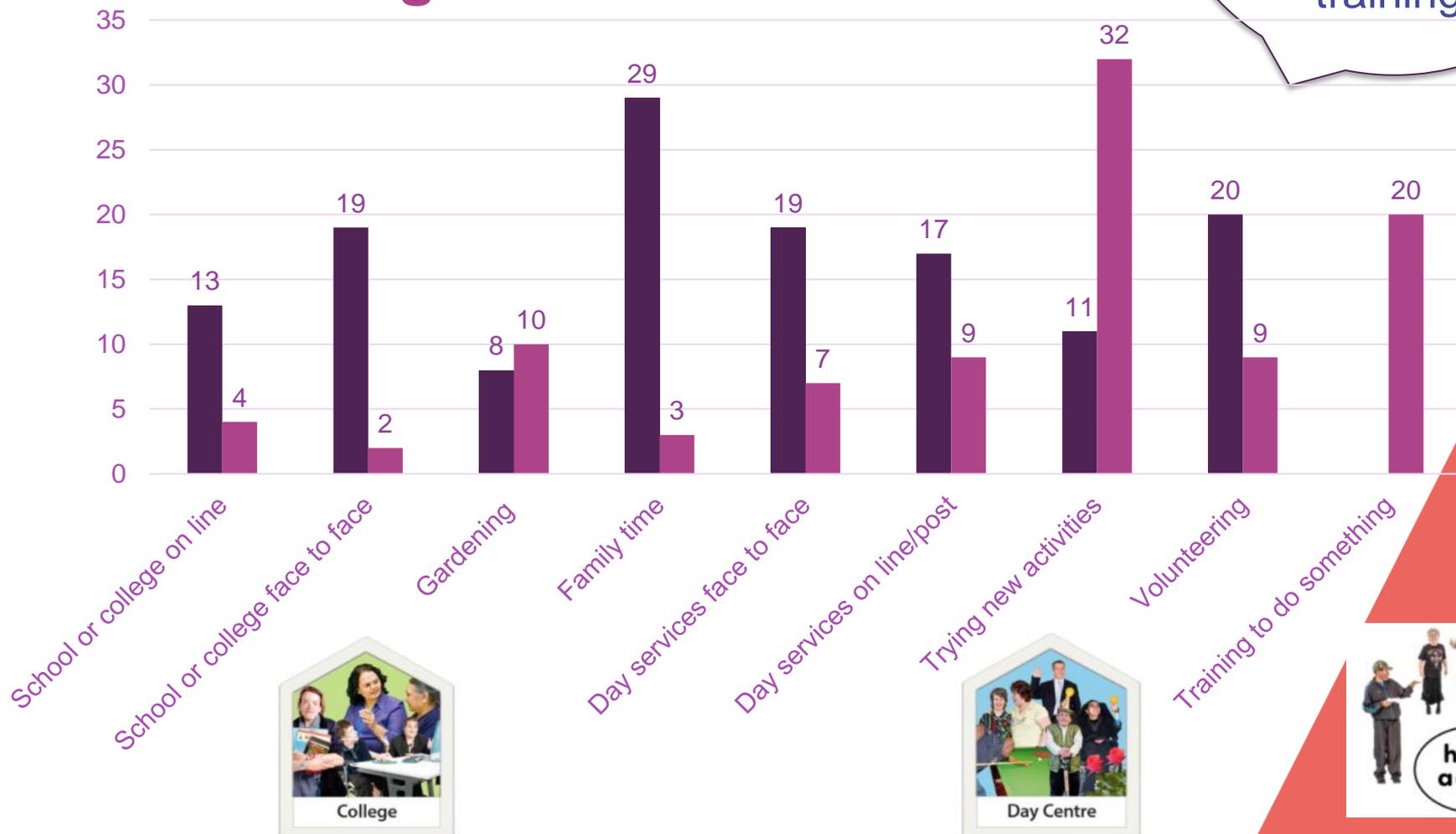
**What do people aged 26+  
want for the future?**

**And what support will  
help them do that?**



## Things we are looking forward to doing again soon or starting to do

- Seeing family
- Face to face day services
- Trying new activities and training



## Other things we are looking forward to doing again soon

- Dance and sports
  - Going out
- Staying away from home
- Shopping and public transport



## Support and training we need to help us achieve our goals

### Activities:

Learn to read  
Golf  
Mending my car  
Making more friends  
Sign language  
Film making  
Music, drums and piano

### Advice and guidance:

Apprenticeships  
Work experience  
Finding out which jobs I could do

### Training:

IT and game development  
Cooking so I can cook for myself  
Assertiveness  
Apprenticeship  
First Aid training  
Work experience  
Typing skills  
Hospital work  
Bricklaying  
Bike mechanic qualifications  
Find out which jobs I could do



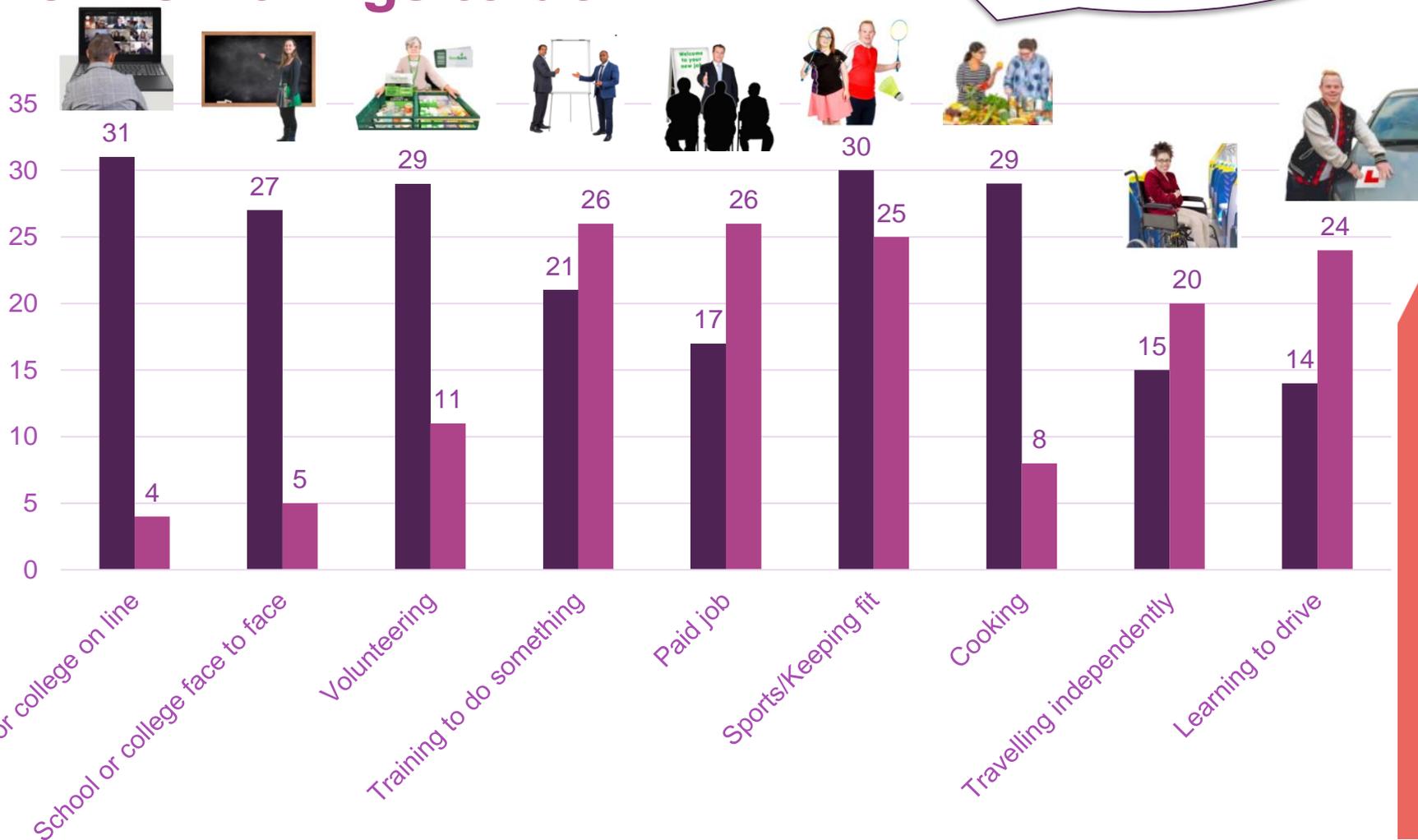
There lots of activities we'd like to try and skills we'd like to learn.

Sometimes we just need someone to come out with us, or to help us to read or cook



## Things we'd like to still be doing in 5 years time or new things to do

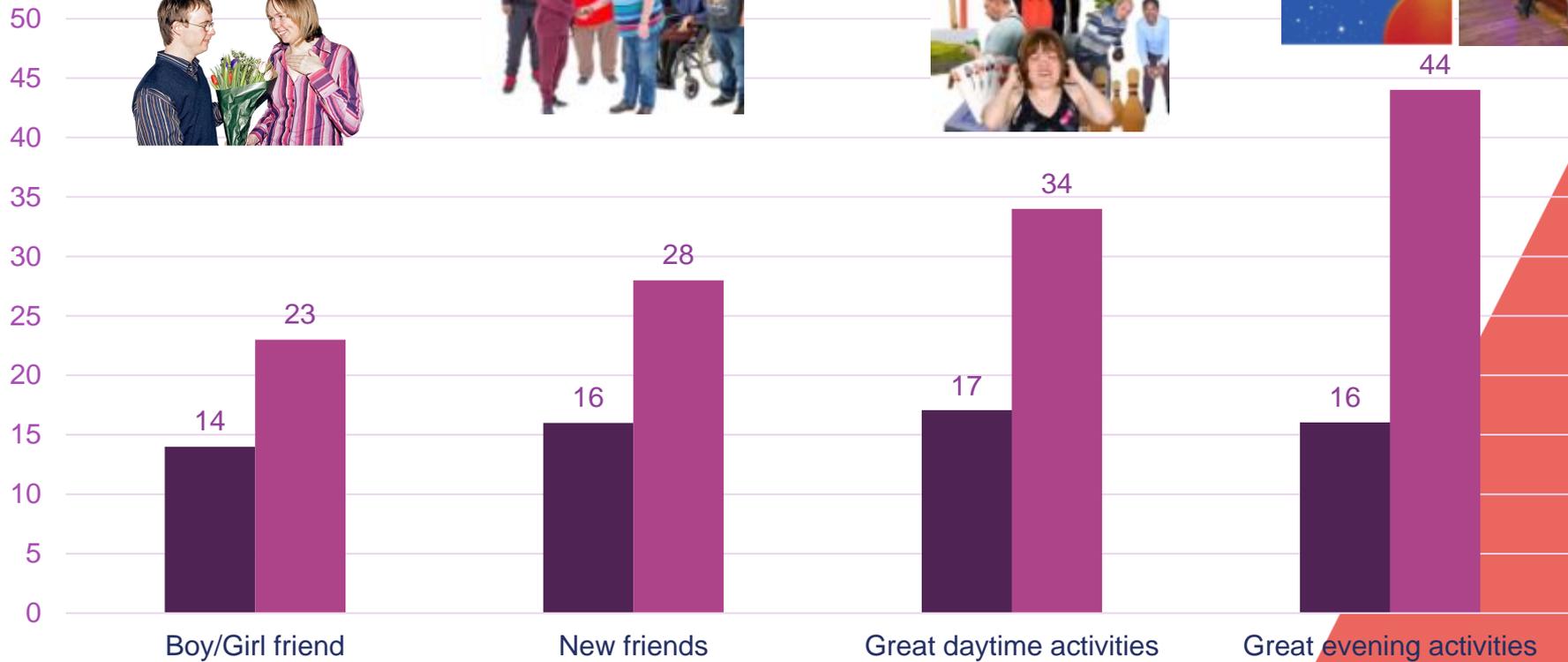
People would like to start Volunteering, Paid work, Sports, Travelling and learning to drive



## Things we'd like to still be doing in 5 years time or new things to do

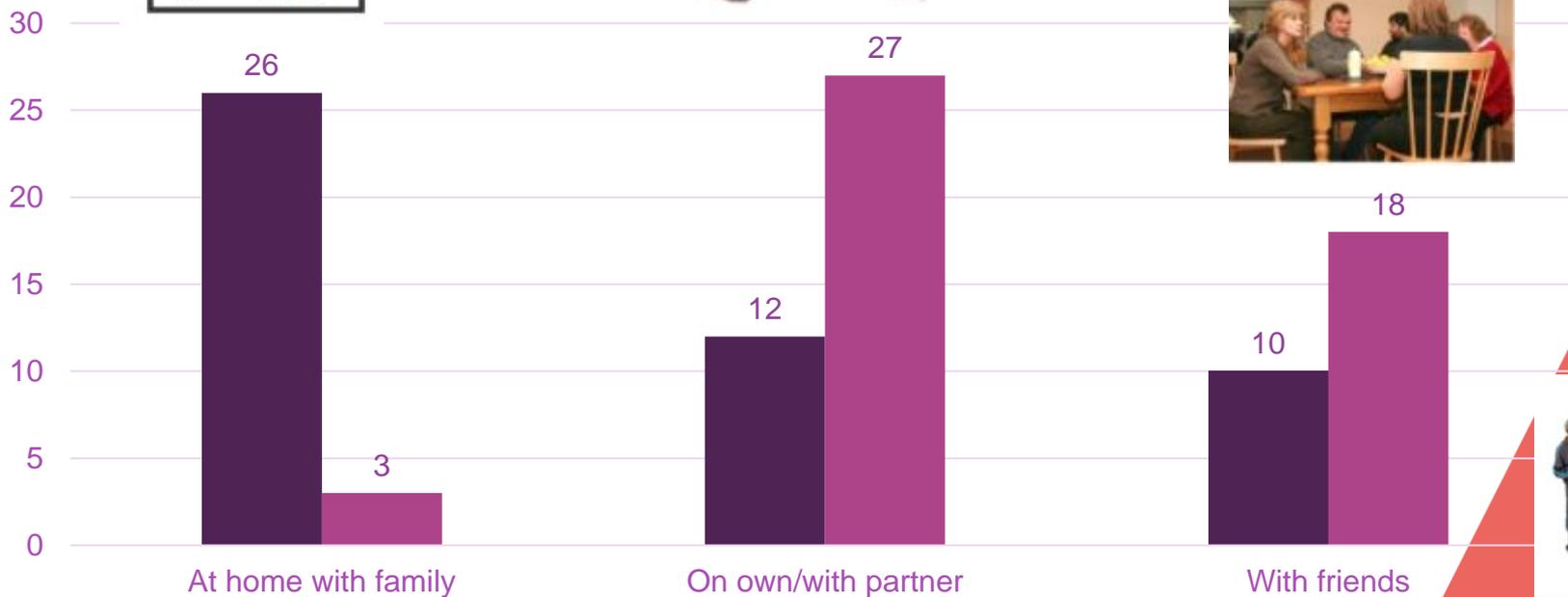
We'd like

- Great evening and day activities
- New friends
- Boy/girl friend



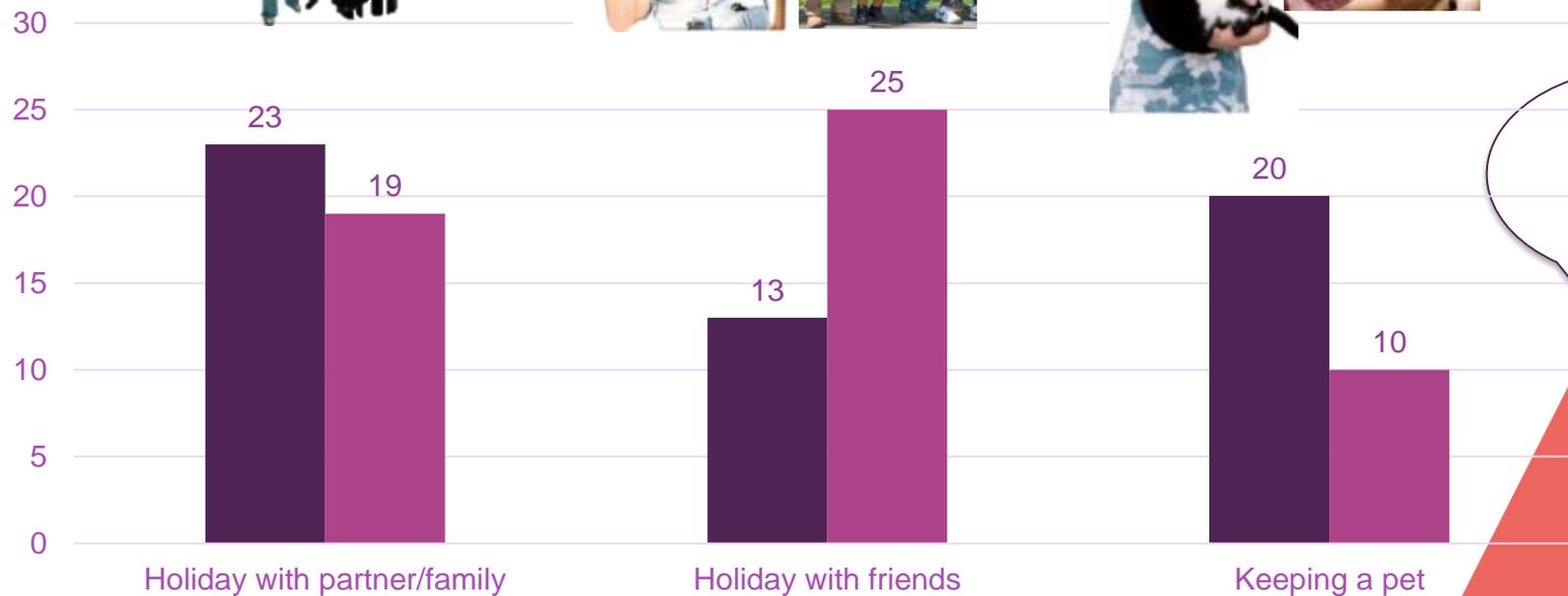
## Where I'd still like to be living in 5 years time or a new home

A lot of people would like to start living on their own, with a partner or with friends



## Things we'd like to still be doing in 5 years time or new things to do

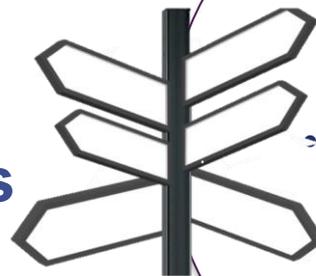
We'd like holidays with a partner/family or our friends



We'd like a pet

## Some things we'd like to do And the support we need to help us

- Art and Artworks
- Baking
- Ballet
- Care Home work experience
- Catering
- CVs
- Drama
- Education
- First Aid training
- General independence skills
- Hospital work experience
- Information about jobs
- Job interview practice
- Online business support and ideas
- Paid job
- postgraduate course
- Online business
- Qualifications
- Skills training around getting a job
- Support Work
- Theatre
- University
- Vocational skills
- Wrestling for the disabled Olympics
- Zoo work experience!



- We need:**
- Advice and guidance
  - Job skills
  - To know more about further education
  - Independent living skills

**My experience.....**

**Laura at Tag Bikes**





# Russell Henke

Speak Out Council Leader:  
High Support Needs



12:05



12:15

What else did people with high support needs tell me?



## No internet

- Some people in Supported Living did not have access to the internet
- They could not take part in any activities online at all
- We think residential or support living contracts, or individual's own care packages, should include a specific mention of IT equipment:
  - regular access to wifi and
  - well qualified support to use it so we can make the most of the opportunities available.

We think supported living contracts and care packages, should include IT and good support so we don't miss out!



## Great news – Funding for internet

The Good Things Foundation is working with Learning Disability England, the Voluntary Organisations Disability Group and Digital Unite to fund IT equipment, data and support.

It is for organisations that already support at least 10 people with a learning disability who are digitally excluded.

[Funding open for devices and data for people with learning disabilities | Good Things Foundation](#)

We have already shared this information with many of you this week. We will put the link in the chat here too. The deadline is now Monday (instead of today)  
Good luck!



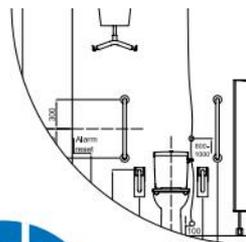
[Funding open for devices and data for people with learning disabilities](#)

## What is important for the future?

Changing Places are really important so that we can enjoy going out and about.

How to find safe clean public disabled toilets is hard

We think there might be some funding for them. We are looking into it.



**Changing Places:**  
the practical guide





## What have I been doing?

### Monthly drop ins on Microsoft Teams

- Find out what people have been doing
- We talk about our latest topic
- Give people chance to raise any issues



I am holding my  
monthly drop ins  
on line

## What else I've been doing?

- Physical Disability Partnership Board
- Healthwatch Greater Cambs Partnership forum
- Regional Treat Me Well workshop
- Along with the rest of the team I have done Prevent training, which is about Radicalisation



**healthwatch**  
Cambridgeshire

**healthwatch**  
Peterborough



prevent people  
from supporting terrorism  
or becoming terrorists  
themselves

Our full report will be available  
on our website soon:  
[www.voiceability.org/speakout](http://www.voiceability.org/speakout)

