



367

KEY Housing

77 Renfrew Street
GLASGOW
G2 3BZ

T 0141-342 1890
F 0141-332 7498

info@keyhousing.org
www.keyhousing.org



Dear Sarah,

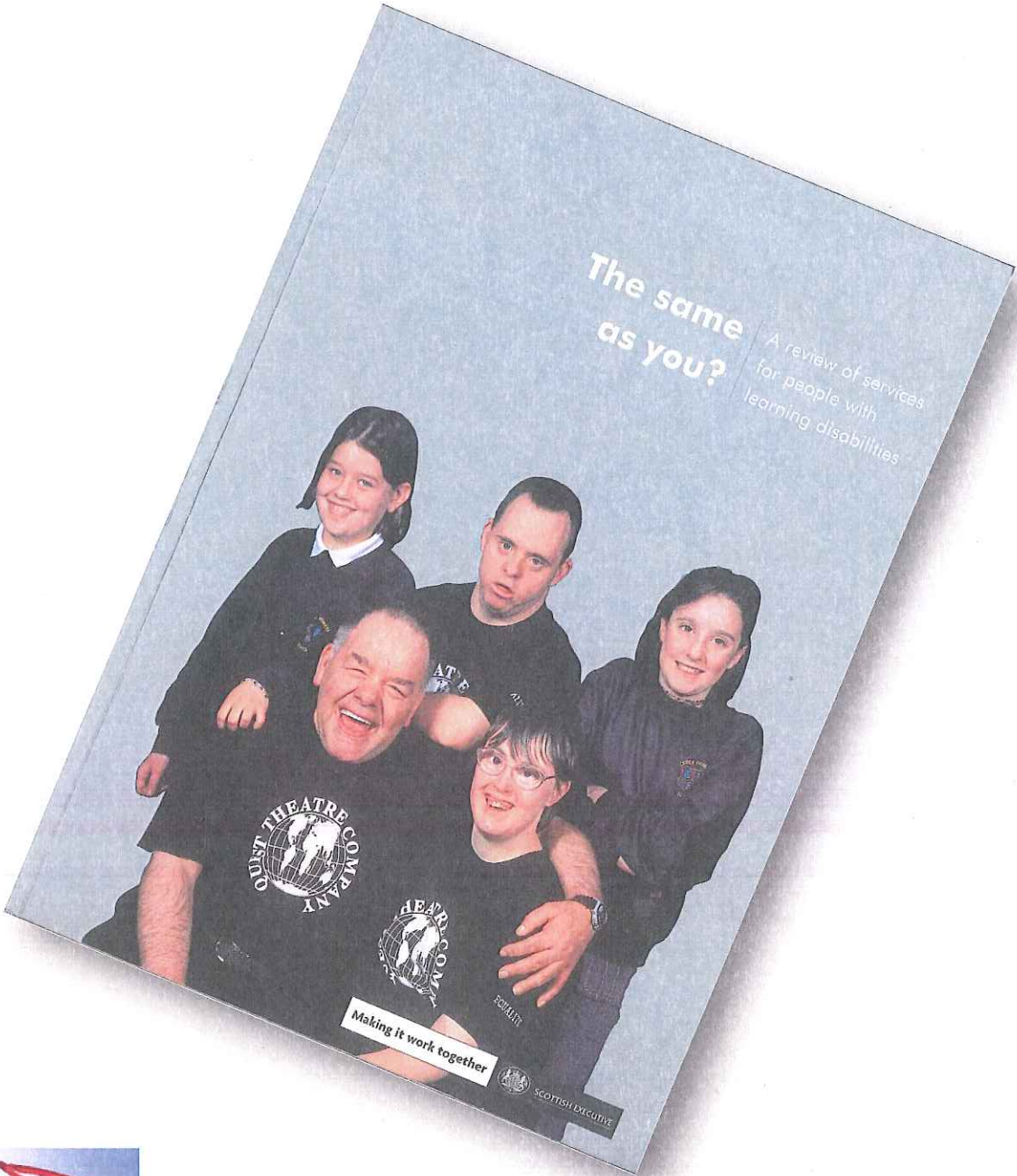
Please find enclosed the results of our *Same as You?* consultation. Over 150 people were involved at 11 events. In addition to the hard copy I have included a DVD which has contributions from people with Learning Disabilities and Family Carers.

Yours sincerely,

Lèam MacKeown
Development Manager
Participation and Inclusion

SAY Consultation 2012

Response from The Advisory Group & KEY Community Supports





The same as you? Consultation Easy Read

This consultation paper is submitted on behalf of:

The Advisory Group(SCIO)



And

KEY Community Supports



77 Renfrew Street
Glasgow
G2 3BZ

Contact person:

Lèam MacKeown

Tel. 0141 342 1876

leam.mackeown@keycommunitysupports.org

An Organisation

The name and address of your organisation will be seen by other people (on the Scottish Government website)

Are you happy for your answers to be seen by other people?

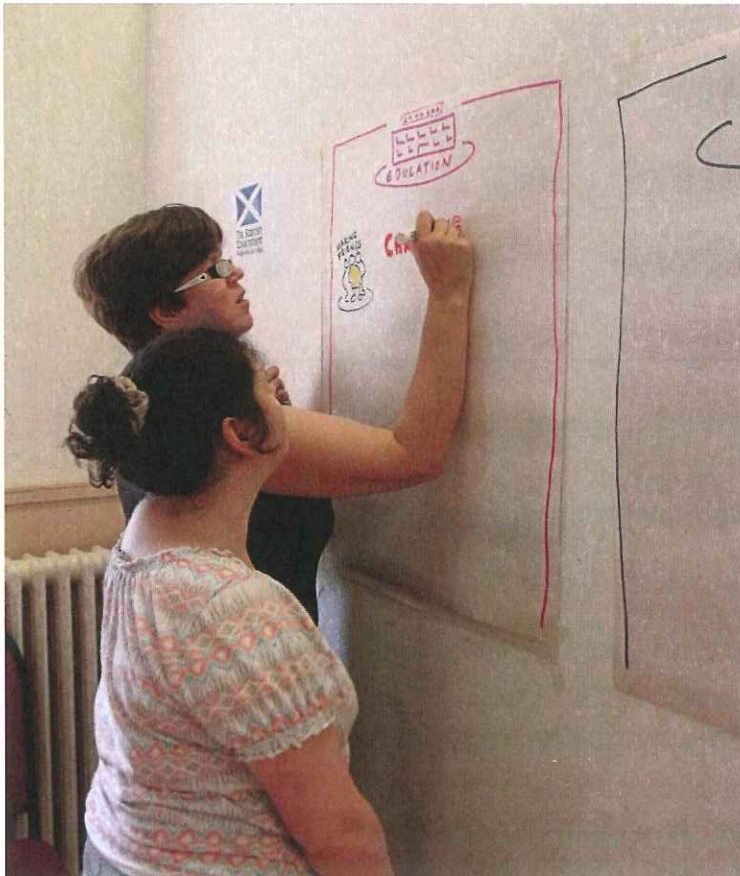
Yes No

Are you happy for the Scottish Government to contact you about your answers?

Yes No

The information in this paper and the accompanying DVD was compiled from 11 events held for people with learning disabilities and family carers by The Advisory Group and KEY Community Supports.

In total around 150 people have taken part in these events. After a summary page for each of the questions we have included some of the graphic recordings produced during our consultation.



Question 1



Do the things in the easy read consultation report reflect your views and opinions about services for people with learning disabilities?

(Please tick your answer)



Yes



No

You can put any comments about this question here.

The report is a good reflection of the improvements that have happened since the *Same as You?*

The main issues causing anxiety are funding cutbacks and changes in benefits. People are very much aware of the times of austerity facing the country. However it is important the Scottish Government ensures that current financial pressures and cuts to public services do not negate the great achievements which were brought about by the *Same as You?*.



Question 2

What do you think has worked well over the last 10 years for people with learning disabilities and family carers?

This could be changes in your local community or all over Scotland.



What has worked well?

People acknowledged that there had been great improvements in the lives of adults with learning disabilities over the past 10 years.

The majority of people have the opportunity to live where they want, with whom they want, fewer people live in hospital or residential care.

People felt very much at the heart of planning their support.

Many people have the opportunity to do more meaningful things in their community (work, voluntary work, community action, sport, leisure and education). Consequently, fewer people attended Day Centres on a full time basis.

Legal awareness of the needs of people with disabilities had improved through things like the Disability Discrimination Act, although people felt there needed to be stronger enforcement.

People's expectation had risen and were less likely to settle for second best.

The establishment of The Advisory Group as a separate charity highlighted the strong voice people had, not only within KEY but in the wider society.

People felt they had greater influence at a national level through the Cross Party Group for Learning Disability at the Scottish Parliament.

People had a direct influence on the running of KEY as an organisation, with service user representation on the Management Committee.





Question 3

What do you think still needs to be done by the Government to make the lives of people with learning disabilities and family carers better?



Summary: ideas for the Scottish Government



The vast majority of people were worried that the great advances made over the past 10 years would be cut short due to funding cuts.

People found the Charging Policy of Local Authorities unfair and a postcode lottery.

While people were in favour of the principle of Self Directed Support and recognised the opportunities it could provide, they were concerned it could be used to cut funding for support.

In keeping with the vision of the *Same as You?*, people are using mainstream services more than ever before. If such services are cut to the extent that they no longer have the time or resources to cater for people with additional needs this could lead to increased isolation and loneliness.

Current legislation (e.g. DDA) needs to be enforced more rigorously.

Although awareness in the wider community has dramatically improved, people felt that more was needed to be done to address negative attitudes. A government led learning disability awareness campaign and a mandatory requirement on the service industries (e.g. bus companies) to include specific training on learning disabilities would be an excellent start.



What could the Scottish Government do better for people with learning disabilities

⇒ Government to listen to US

⇒ More information to be given on what is on in the community. Section in paper

⇒ Bigger budgets

⇒ Be able to do a job but not want benefits to be cut

⇒ Correct support

⇒ Do more to treat us as ~~ordain~~ ordinary people

⇒ Giving people more education



The Scottish
Government
Riaghaltas na h-Alba

Make sure the disability
access laws are obeyed.

Check up on shops etc.

Access on the pavements/Roads
is bad → Dodgy parking!

We would like the Government^{to} be aware of...

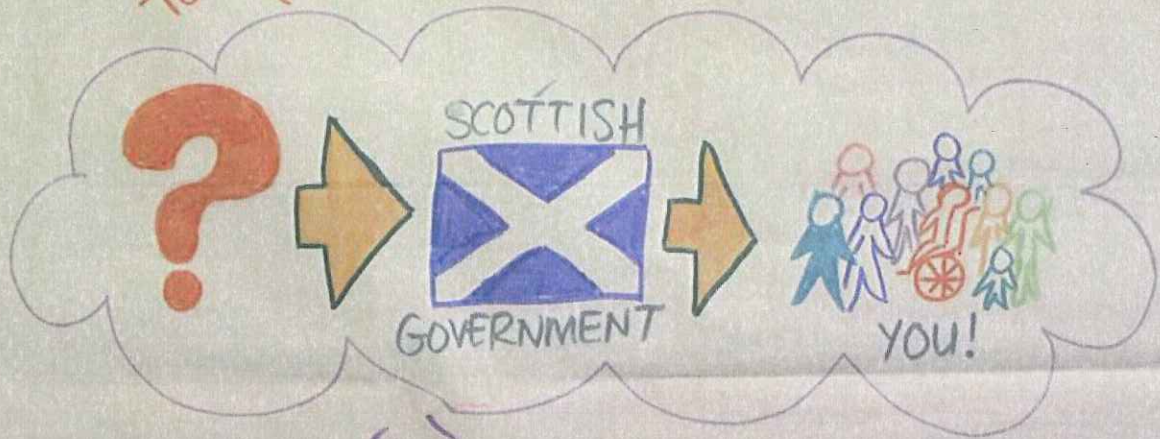
- Charging policy - we need to understand why this is being paid, what's it for?
- Families want to know more about the Welfare Reform Bill, this information needs to be accessible for us.
- It is a real worry about how our sons/daughters/relatives are going to be affected by potential cuts in benefits.
- How can our relatives continue to live a busy, meaningful life if benefits are being cut?
- Seems to be discrepancies between what people are paying in charging policy - this needs to be looked at. If someone can't pay the charging policy there may be a decision to refuse support, what happens then?
- People are getting older - families and people accessing services - worried about the future - what's going to happen?
- Think about people with smaller support packages - people are still really vulnerable.
- D.L.A - for a lot of people - phone call assessments are completely impossible - There has to be a face to face assessment.
- Worry about the discrepancies between local authorities in terms of what is being introduced. (Self Directed Support)
- Could providers and authorities work together to look at what people need - yearly basis - but not based on introducing cuts - Needs to be based on people's actual needs.
- Access to public transport for people desperately needs to be improved. Public transport is really problematic for people.

MESSAGE TO THE GOVERNMENT.....

- Finances — There are differences between what (charging Policy) local authorities are charging people. Feel local authorities should be brought into line with this.
- Do not cut funding!
- There has to be face to face consultation - only this method will ensure car family members get a fair deal.
↳ This also must include input from people who know the person well.
- It's frightening that decisions are being made by people (Government strategy) who do not understand the needs of people with learning disabilities.
- People need that one to one contact! This provides security for people.
- The Government needs to ensure financial security for car family members.
- We must continue to consult with the people who are receiving support.
- Cheaper does not mean better!!
- Don't interfere - Don't fix things that aren't broke!
- Have more consultation with family members and with people who receive support.

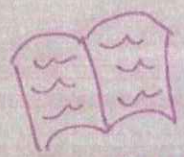
AWARD STARS
TO SHOPS/BUILDING
FOR GOOD ACCESS

COMMENT CARD



IMPROVE
ACCESS - PRIORITIZE
PAVEMENTS!

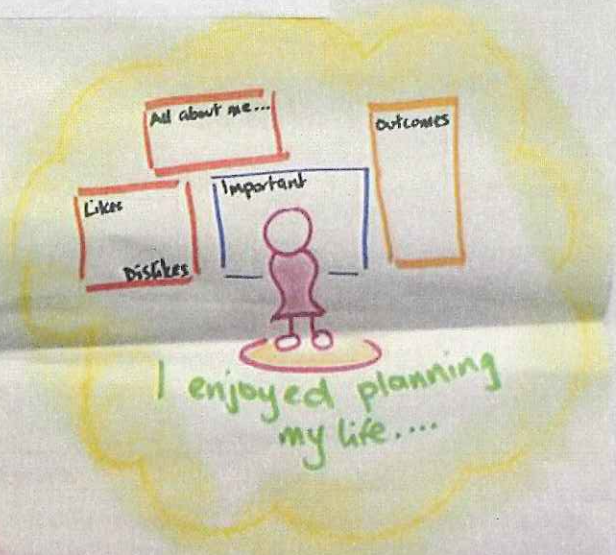
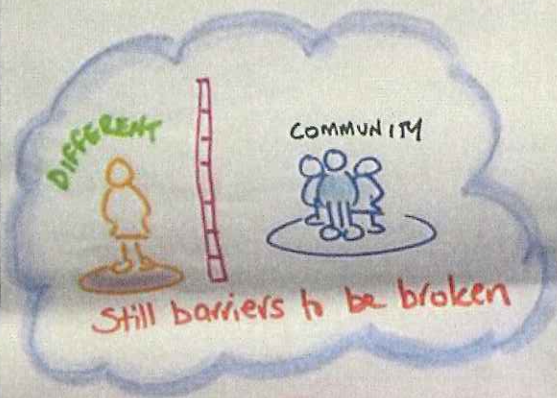
COURTESY
COURSES
FOR PEOPLE
WORKING IN PUBLIC



ANTI-DISCRIMINATION
EDUCATION ADDED
TO CURRICULUM.



The Scottish Government
Riaghaltas na h-Alba





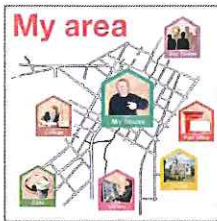
Question 4 - (this question is for organisations only)

- What have you done in your organisation to improve services for people with learning disabilities in your local area?

In 1996 KEY Community Supports established The Advisory Group (TAG) as a forum to ensure the people it supported had a voice in the running of the organisation. This group was particularly involved in the original SAY consultation.

Over the years TAG has guided KEY in the provision of individual personalised services. Together they have worked to promote social inclusion and participation throughout Scotland. They have worked together to challenge discrimination and create new opportunities for people with learning disabilities to live full and active lives as part of their community.

This has included: The employment of people with learning disabilities as co-trainers, individual accessible planning service, the creation of 9 TAG branches, employment initiatives, inclusion training, a disability awareness schools programme, networking projects, active engagement with SDS, TAG representation on KEY's Management Committee and a host of other initiatives to ensure people with learning disabilities have choice and control over their own lives. In February this year The Advisory Group became a registered charity in its own right with nearly 200 members. This is a testimony to KEY's commitment to inclusion.



Question 5

What have you done to make things better in your local area for people with learning disabilities and family carers?

KEY and the people we support have made things better for people with learning disabilities and family carers in local areas by:

Volunteering and promoting volunteering

Campaigning with others to improve local facilities (e.g. Pavements, road crossings, public transport, etc).

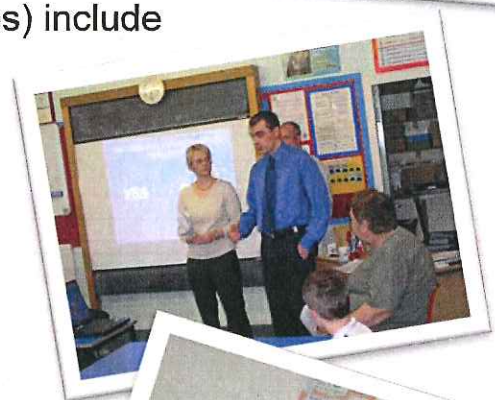
Working with and through local 'Networkers' to improve the way in which mainstream facilities (leisure centres/clubs/community venues) include people with disabilities

Working with schools groups in relation to disability awareness and anti-discrimination

Supporting the work of Scottish Consortium for Learning Disability

Providing access to affordable and where necessary adapted housing

Providing person centred support to enable people to live and participate in their community.





Question 6

What do you think needs to be done to help people with learning disabilities get access to good healthcare?



Summary points on Health

People were generally very pleased with the developments in health care.

People felt they were treated with dignity and respect by nurses, doctors and other health professionals.

Medical staff were more aware of the needs of people with learning disabilities, especially those who had qualified within the last 10 years.

Medical staff were more likely to take the time to explain things to people without using complicated words.

People found it much easier to access general health improvement information.

On the negative side,

There was still an issue about doctors putting medical symptoms down to the nature of a person's learning disability, without carrying out a proper medical evaluation.

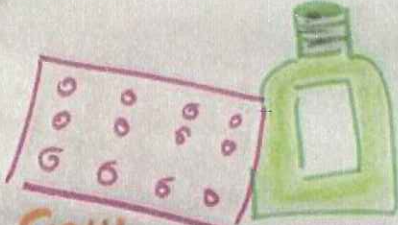





HEALTH

Waiting List
~~~~~  
~~~~~  
~~~~~

Like to see smaller waiting lists + times at hospital



Getting Medication Right for my epilepsy!!



Good advice to be healthy (lost weight)



FEEL GREAT



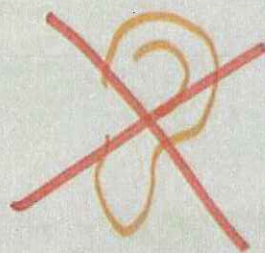
Treat me like an adult.

Happy

GPs need more training in disabilities.



Hospitals not listening.



→ Attitude

Lack of Information

→ Should get better at arranging appointments.

Some GPs + Health centres are brilliant.

Good experience of Dentists

→ Good at taking the time to explain things to people who are anxious

Problems accessing health services in rural areas.



# HEALTHY

- Experience of health care has been good.
- Support workers can often pick up on my daughters health care needs. Good quality support is provided.
- Feel that my brother's health care needs are not being addressed. Health issues going on for two years.
- Lack of information, as a family we have often not been told about appointments.
- Communication about health issues between professionals and family members not always good.
- Whenever we have asked for anything from our carers, it has happened!
- Worried about cutbacks, which will impact on continuity of staff, directly affecting support offered to my sister.
- Worried is the money going to be there?  
What's going to happen to people if the money is not there?
- G.P.'s don't always know the person well / don't always have the right attitude!
- Community learning Disability nurse - we need more of them!  
- they are more aware of what people need.
- Nursing care has improved.
- Inform families about Charter's for funeral plan - put a booklet together.

## Health continued.

- Sometimes health care professionals can be too quick to put a D.N.R. in place for someone with complex needs.
- Health care professionals will not always consult with family members about this issue.
- It is absolutely crucial that if a son/daughter is in hospital, that they have someone in hospital (worker) who knows them well. This makes sure that we can advocate for that person.
- Real concern that there might not be the money in place so that hospitals can provide the care that my sister needs.
- Gap exists between the community nurses and NHS nurses/staff.
- Feel that more could be done to educate health board/NHS staff about people with learning disability.

## Health continued.


- Continuity of health care is crucial.
- Change is really difficult for families and family member - consistency of support provider/health care workers makes this easier.
- One to one support makes health care appointments much easier.





## HEALTH

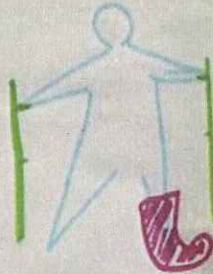
- Feel that health is well monitored.
- There have been times when there hasn't been a consistent team, which impacted on family member health - increases confidence.
- When there is a team around a family member this ensures best quality. Continuity of workers crucial!
- Happy with level of care being provided.

  
Good Doctors

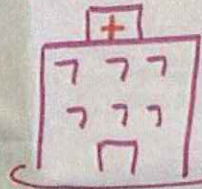


Talk to us...  
Not my worker!!

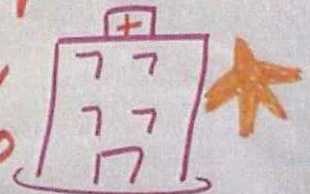
  
Good dentists



Good hospital Care



10/10



WESTERN

GOLDEN JUBILEE



Training for medical  
staff has got much  
better!



Good  
Communication

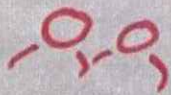


$\frac{10}{10}$

Has got much better!

Dentists  
are

really good.

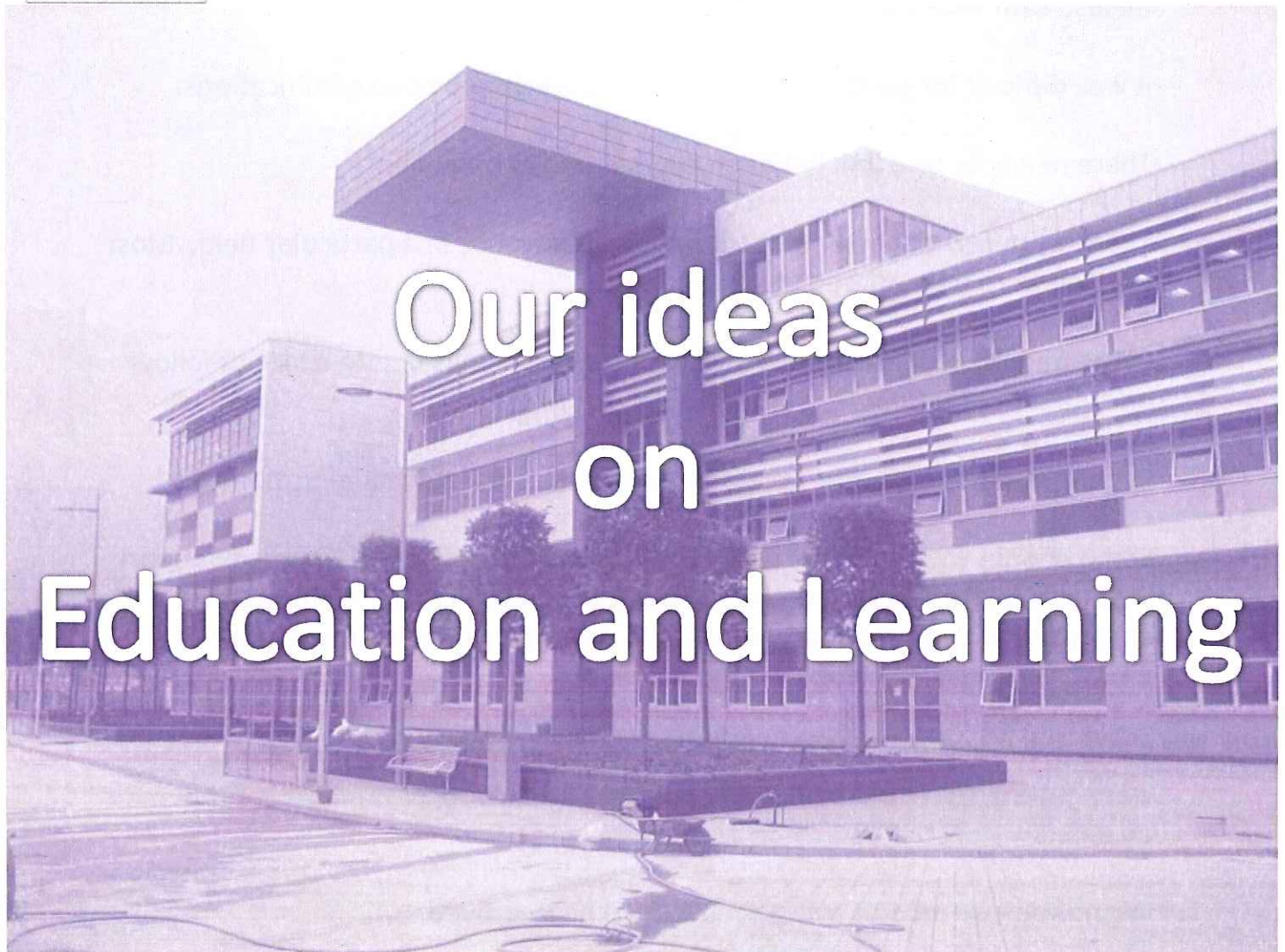


Talk to me and  
my worker.



### Question 7

What do you think needs to be done to improve access to better education and learning for people with learning disabilities?



# *Summary points on Education*

People had felt the impact of funding cuts on college places. This had resulted in a gap in some people's lives. Rarely were people given an alternative when their time at college came to an end.

There was still a lack of support from the colleges for people to attend mainstream courses.

It was difficult for people to access courses which provided qualifications.

There needs to be a link between courses and employment.

There were few opportunities for people to advance in a particular field. Most courses were only offered at a basic level.

Often people repeated the same course several times due to a lack of follow on courses.

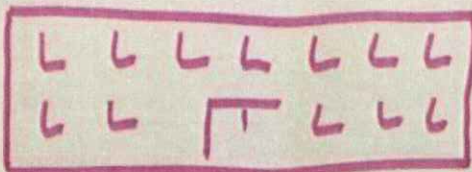
People would like greater access to evening classes, individual tuition etc.

Some people with personal budgets allocated through a Self Directed Support Resource Allocation System, had to decide between crucial home support and continuing with a secondary provider in an activity they enjoyed and promoted social inclusion.

Some third sector organisations which provide excellent learning opportunities were getting squeezed by funding cuts and are no longer affordable for people on an individual budget.

Information on what is available needs to be improved.





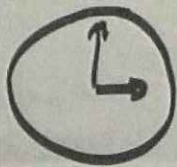
EDUCATION



- Always the same courses.

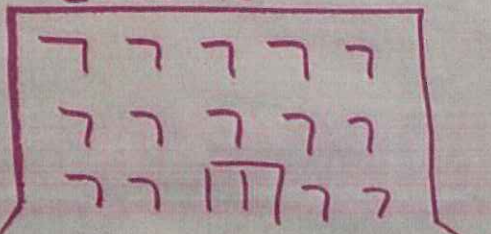


- No follow up, step up courses.



Difficult to find different times for courses.

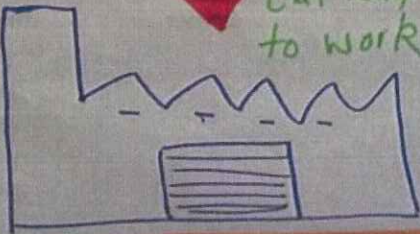
COLLEGE



work

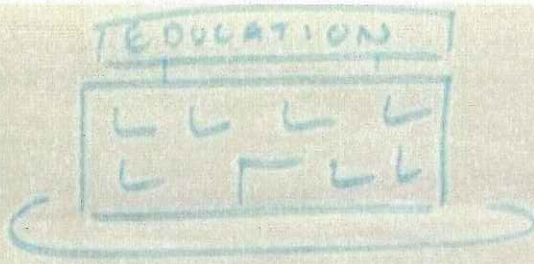


Courses that lead to work...

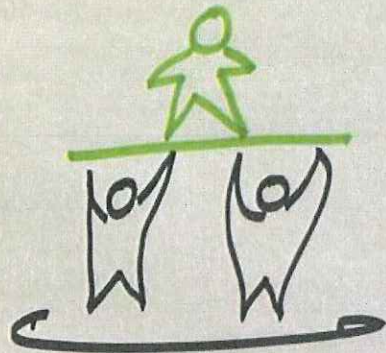


AWARDS FOR COURSES...

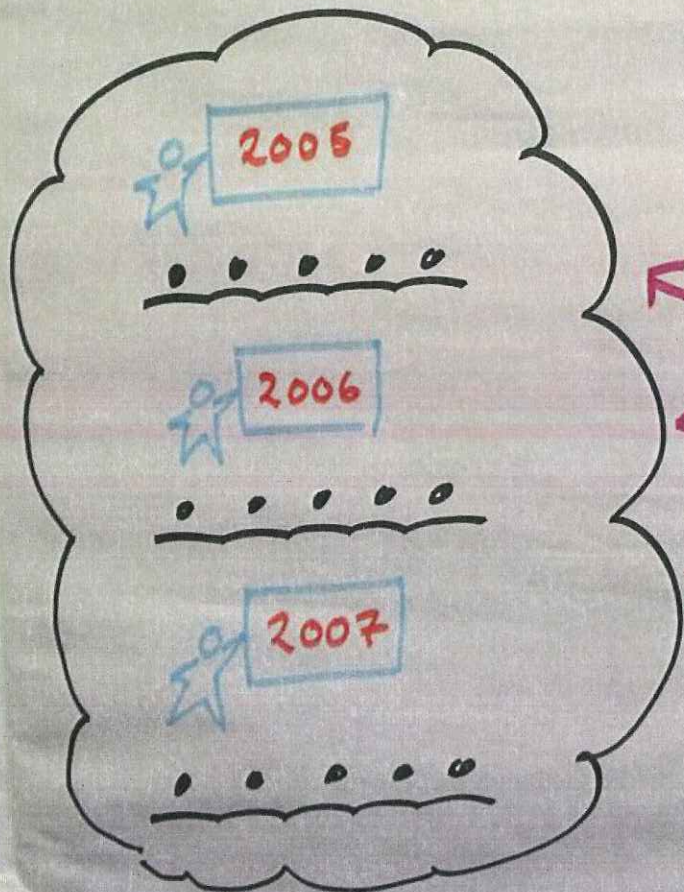
SVQ, CALEDONIAN DUKE OF EDINBURGH



Need better information.



Need better support from colleges.



Same courses over and over again...

COLLEGE



# EDUCATION

BLAH!

BLAH!

# CHATTING

BLAH!

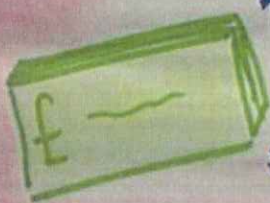
MAKING FRIENDS



Being Busy Gardening

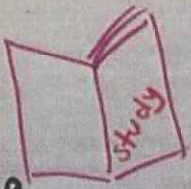
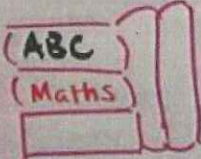


Wider range of courses



↑ Like more funding so I can get a place

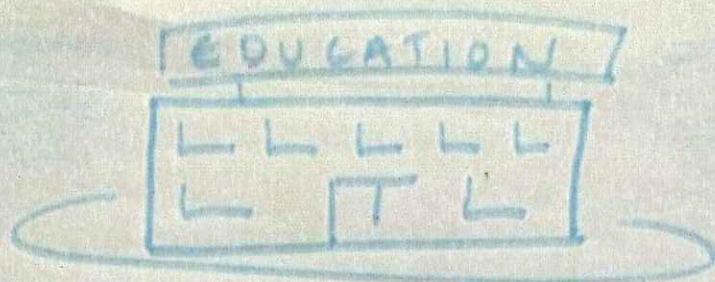
WHAT WE THINK ABOUT EDUCATION...



Learning New Things







Glasgow gives  
good additional support

Stow college  
was very good.

Follow on courses  
are needed.

College courses  
are being cut.

Some courses are  
a waste of time.



Need better info  
on what's on.

More courses leading  
to qualifications.



People need more support  
to attend 'mainstream'  
courses + colleges.



### Question 8

What do you think needs to be done to help people with learning disabilities live more independent lives?



# Summary points on Independence

People agreed that they had much more choice and control over their lives.

People valued being involved in their local community.

Having the right support to be as independent as possible was vital.

People wanted the support to do the things they wanted and were worried that funding cuts would mean they could only get support to do the most basic things: The difference between simply surviving and living a full life in line with the aspirations of *the Same as You?*.

In some areas the charging policy was having an impact on the amount of money people had left to live on.

People were worried that funding cuts meant an increase in shared support rather than having their own place in line with the *Same as You?*.

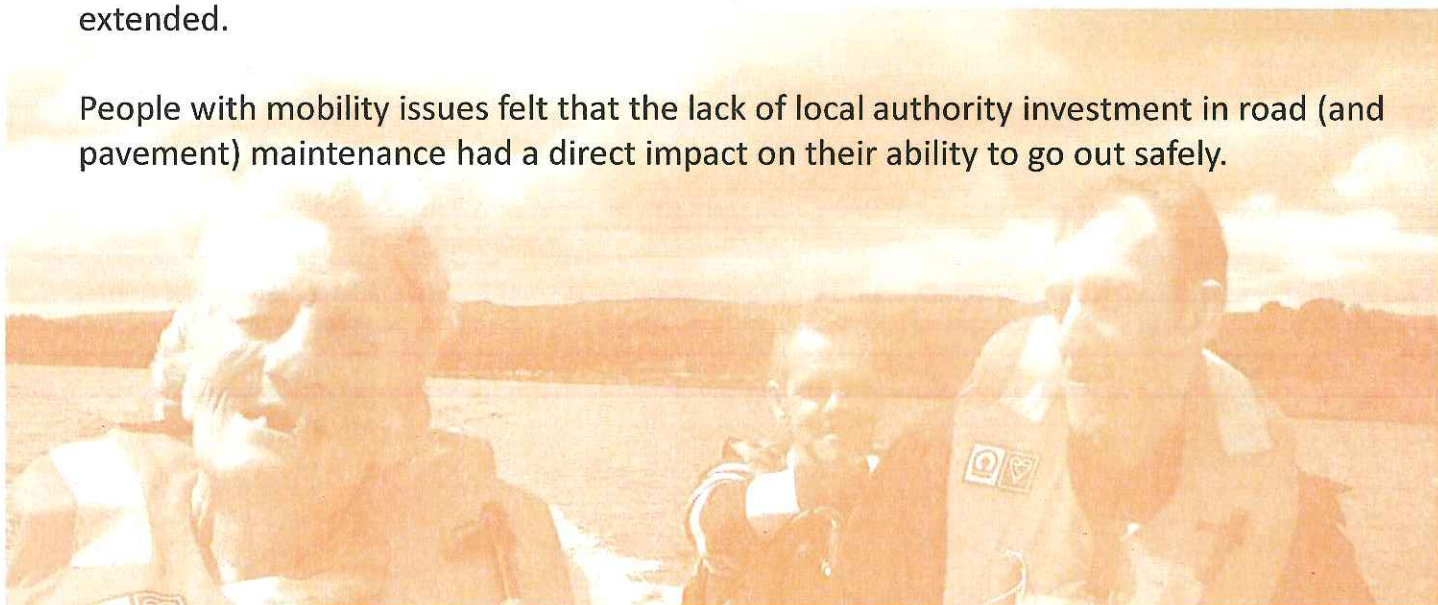
People valued affordable housing in safe areas.

People valued self advocacy and the opportunity of being listened to.

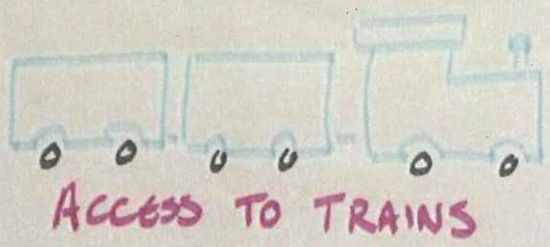
Attitudes to people with learning disabilities on public transport is still a problem and further investment in disability awareness training for bus drivers, taxi drivers and rail employees is required.

Lack of public transport in some areas still causes specific problems for people with learning disabilities, most of whom do not drive. Dial-a-bus provision could be extended.

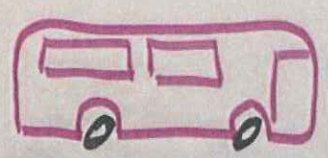
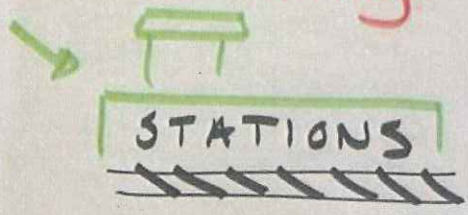
People with mobility issues felt that the lack of local authority investment in road (and pavement) maintenance had a direct impact on their ability to go out safely.



**INDEPENDENCE...**

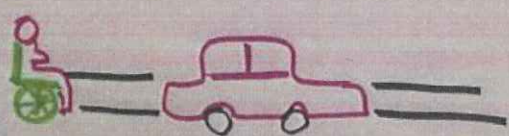
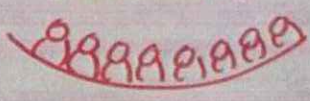


Safety while travelling.



Changes and charges for Disabled parking.  
→ Varies from L.A to L.A.

Buses changing route.  
Accessible Information for transport



Parking on pavements

Campaign to raise awareness amongst the general public.

Kinder Scotland.



## INDEPENDENCE..

- Move away from institutional care has been tremendous for our cousin. Increased freedom!
- Still seeing the aftermath of Lennox Castle for our family members.
- People need to have their own homes, with the right support around them.
- Feel fully informed about what is happening in our family member's lives.
- Have been on a journey to get the right accommodation for our cousin.
- Responsive services helped!
- Financial support needs to match what family members (who receive support) need!
- There is a real concern that Local Authorities may still consider tendering services. This does not provide the best quality of service & support for people.
- Need to make sure that if people are living together they are compatible.
- Community - people are more accepting of people, more of a sense of local community!  
Neighbors speak to each other / know each other.
- Good quality housing / neighborhoods have to place people in appropriate houses / environments.
- Services - Like KEY have to be continued to be funded.
- Our family members need this service.
- Giving thought to planning - Funeral bond / charter / consultation with family.



# INDEPENDENCE

- Having more access to public transport example to bus stops, nearer my son's house. Making it easier to get on and off.
- Buses not accessible for people, making it difficult to get to places.
- People who receive services, need people to advocate for them. Particularly if people do not have large families. Someone to speak on the person's behalf.
- It would be helpful for families to have more information about what is happening.
- For example if North Yorkshire Council are implementing changes, families feeling they would not find out.
- Newsletter from Key - Monthly update - people felt this would be really helpful
- Establishing good relationships between families, care providers crucial to ensuring best quality support for the person receiving a service.
- Service provider - when a provider is being selected not always given enough access to the provider or given a choice about who the provider is.
- Family members feeling the situation is better now, have more information. In the past we had no control.
- All workers being aware & support plan - Ensuring the people supporting or family members know the person.

# INDEPENDANT LIFE

OWN FRONT DOOR.

NO DISAGREEMENTS OVER TV, and other Household items.

ITS MINE!

MY OWN CHOICES / ROUTINE / TIMES  
(MORE)

NOT HAVING TO SHARE

PRIVACY!! \* Margaret

1 to 1 HOLIDAYS INSTEAD OF GROUP

QUIET TIME \* Agnes

# YOUR INDEPENDENCE



ACCESSIBLE  
INFO

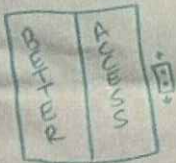
ENCOURAGEMENT  
&  
GUIDANCE

BULLYING  
HARRASMENT

WHAT



HELPS?



CONSISTENCY  
IN  
SUPPORT



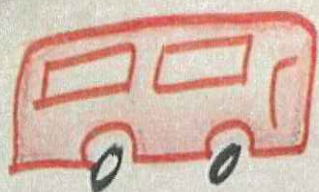
HEALTH  
+  
ISSUES



UNHELPFUL  
PUBLIC/  
SHOPKEEPERS/  
BUS DRIVERS etc.



INDEPENDENCE



Lack of accessible Buses.



Poor attitude.



State of Roads.



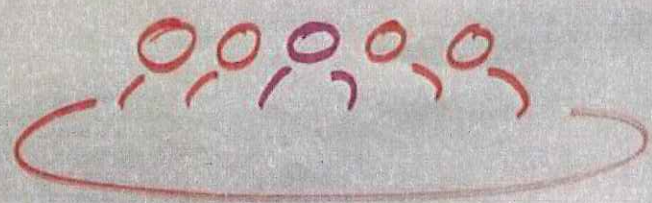
Charging Policy (Real impact on people)

Lack of money.

Attitudes and Lack



But there are some really good people.



of understanding in Society

## Independence

- Feel as if I can come in and talk to people to sort out problems.
- Feel that it's difficult to get the communication that we need to sort out issues.
- Frustrating when companies (Electricity / Gas) don't understand that our family members have a learning disability.
- What's needed is learning disability awareness for these companies.
- In the community in general there is generally more acceptance because people are living in their local communities, increased visibility.
- Could a document be put together to stop banks, providers, etc from being unable to speak to family members?
  - Something that would flag up the person's details, for example - financial guardianship is in place -
  - Something that would make communication easier.
  - Data Protection - has to be taken into account, have to protect our family members.
  - Needs a balance, to increase understanding but to make sure financial safeguards are in place.

## INTERESTING THINGS TO DO

- Day trips - having places to go / things to do.  
- We would like our brother to have the opportunity to do this as much as possible.
- Activities need to be matched to people's preferences, interests. Continuity of support is really important to make this happen. Having small teams around people!
- Person centred approach works, understanding that for our family members to make informed choices, they need support to make decisions
- There is a feeling that the Government is starting to look ahead for our family members
- There should be more access for employment opportunities, that suit each individual. It should be easier to do this!!

★ What are the things that help you live independently

- ⇒ Freedom to go out and about meeting new friends
- ⇒ Having own house
- ⇒ Travel on your own
- ⇒ Having own money
- ⇒ Getting support to be independent
- ⇒ Going on holiday's / Socialising
- ⇒ Making your own choices / own decisions
- ⇒ Going out with worker - safe with worker - Peace of mind knowing a worker at hand

⇒ Doing homework / cooking / different clubs

⇒ Giving opportunity to try new things

- ⇒ Being given the confidence to try new things.
- ⇒ Support workers help to get known in the community
- ⇒ Boatclub - new friends
- ⇒ Stand up for your own rights
- ⇒ Important people speak slowly for slurs
- ⇒ Support plans - How you want to live your life
- ⇒ Mobility scheme
- ⇒ Freedom of speech. Important to be asked - to be given the choice
- ⇒ Taking risks - Try new things
- ⇒ Making own appointments for Doctors / Dentist
- ⇒ Family - Important
- ⇒ Workers to attend classes (Art)

⇒ Having correct equipment in your own house to support your needs

⇒ Own vehicle - to get about with support of a worker

⇒ Tell worker report fault

⇒ Tunstall - fire <sup>Bield</sup> check / smoke alarm

⇒ Annual Electric check

⇒ Workers help read mail / more graphics

⇒ Key connections / Magazine

⇒ Projectability - Got a lot out of it.  
Really enjoyed.  
Great memories / ~~the~~  
good / bad  
Views about their lives.



### Question 9

What do you think needs to be done to help people with learning disabilities get jobs?



# *Summary points on Employment*

Very few people had paid employment.

There were very few opportunities for part time employment.

The benefit system is a barrier to people getting part time employment and people were concerned that the Welfare Reform Bill would not improve matters.

The few people who had had experience of paid employment had found it very difficult working through the benefit system. In a number of cases the experience had been so bad that it would stop them looking for work in the future.

Benefit staff could be more helpful and appropriate forms and information can be hard to come by.

People were often financially worse off when they took a part-time job.

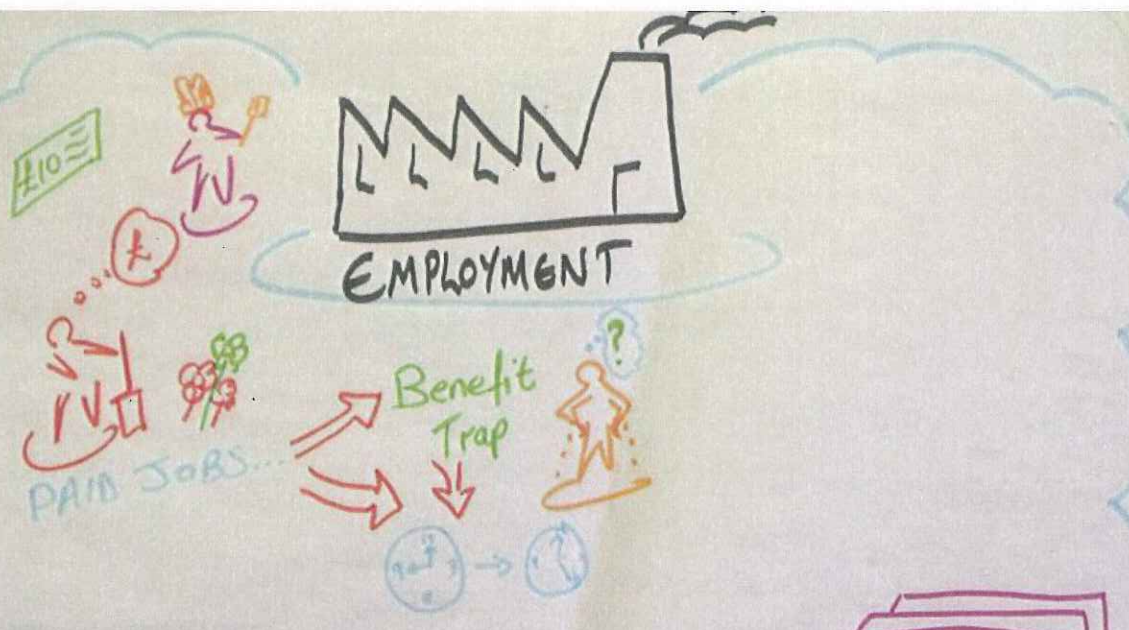
A few people benefit from the £20 disregard which allows them to be employed for a small number of hours (e.g. As co-trainers in KEY). People were worried that this would stop once the Welfare Reform Bill comes into force.

There was a lack of support for people to be able to maintain jobs.

Most people were involved in some type of voluntary work and greatly valued the impact this had on their lives.







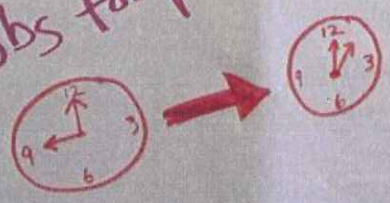
COLLEGE

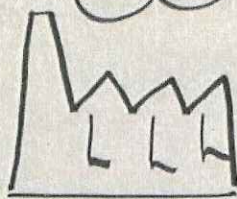
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Real Courses... Real Jobs...

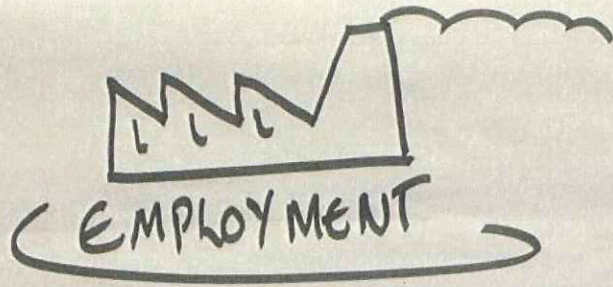
More part-time jobs for people.





## EMPLOYMENT

- College - my son attends college has a busy life.
- Worried about what is happening during the day, boredom, feel that there were more things happening in the past.
- College funding has been cut, not enough courses.
- More community based activities needed, that people could go to.
- Transition 16-18yrs Government needs to give more thought to having things in place for people of this age. Particularly for people with more complex needs.
- Should the transition age be extended from 18 to 24?
- More investment - so that people have meaningful activities to do.
- Sport - people need access to sporting facilities/classes.
- Attending activities can sometimes be costly for my son, if he has to pay for two workers. Cost can be prohibitive.
- Could thought be given to encouraging facilities to allow careers to go for free?
- More information about finances would be helpful - how costs are broken down. More information about benefits, long term financial planning for families.



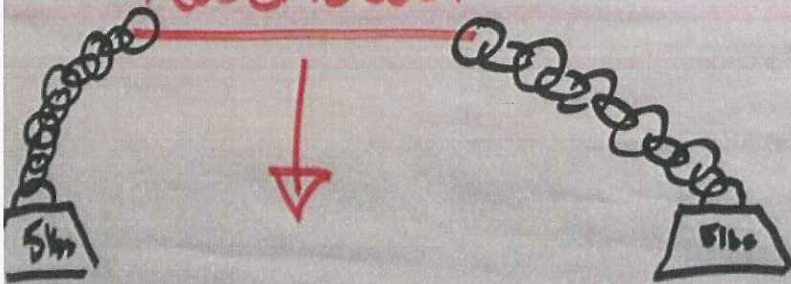
Before

After

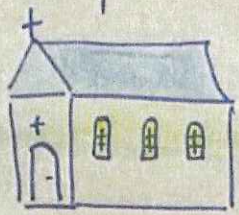
Discrimination



Restricted

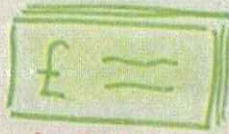


# EMPLOYMENT



I Like hard Work  
stacking shelves  
in Church

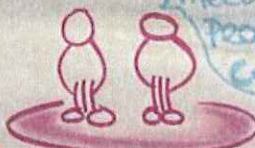
BEING VALUED



+ PAID



Meeting  
People!  
Company.



I should be  
treated the  
same as  
everyone else!!  
...+ get paid

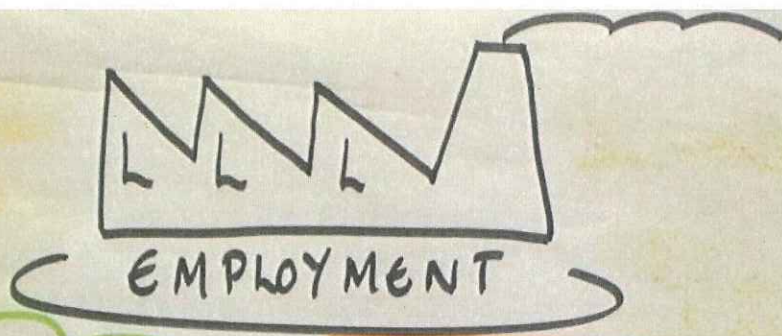
**LACK OF  
SUPPORT**



Important  
to be busy

Worried about  
benefits





More support  
for people to go  
to work.

'New Deal'  
didn't help.

There is still prejudice

£ = Part-time  
job -  
Worse  
off.  
Extra bills.

Smaller organisations  
are more welcoming.

Some jobs are  
difficult for people.

Benefits can stop  
people going for  
paid work.



### Question 10

What do you think are the things we need to do in the future to make the lives of people with learning disabilities better?

Please write the most important things first.



1. Maintain the vision of the *Same as You?*. Ensure that the current austerity measures don't lead to a loss of momentum or even worse a return to the institutional models of care where cost rather than quality is the driving force.
2. Continue to promote an equal Scotland where everyone is valued for who they are and where people with learning disabilities are seen as contributing active citizens.
3. Promote the introduction of Self Directed Support, but as a means to give people control over their lives and not as a way for local authorities to save money.
4. Address issues relating to the Charging Policy and ensure Welfare and Benefit Reform does not adversely effect people with Learning Disabilities.

