



People First (Scotland)

Citizens' Grand Jury Report



**Care, Protection and Human Rights or
Danger, Neglect and Human Wrongs?**

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About People First (Scotland)

People First (Scotland) started in 1989. It is the independent self-advocacy organisation in Scotland.

We are run by and for people with learning difficulties. We say that there are 3 things we try to change:

1. The way people with learning difficulties see themselves - most of us have grown up believing that we are not much use; that we have nothing useful to say and that we can do nothing for ourselves or anyone else. We know that's not true but we need to work at changing how we see ourselves.

2. The way the world sees and thinks about people with learning difficulties - most people in our communities believe that, at best, we are "poor souls" and, at worst, that we are a nuisance and a drain on society. This has to change.

3. The law and policy as it affects people with learning difficulties - our lives are often ruled and directed by laws and policies that we have had no say in. One of our mottos is "nothing about us without us" and these days, Government and local government usually tries hard to listen to our points of view.



Monica Hunter, Jury Chairperson

About the Citizens' Grand Jury

The People First (Scotland) Citizens' Grand Jury was held in Edinburgh City Chambers over two days on 26th and 27th January 2011. The event was entirely run by people with learning difficulties. The twelve people who made up the Jury itself were all members of People First (Scotland).

During the two days, people with learning difficulties gave evidence about their own experiences and expert witnesses were asked questions about key issues in the lives of people with learning difficulties in Scotland today.

The aims of the event were:

- To learn from the experience of people with learning difficulties.
- To ask searching and challenging questions of other witnesses.

The Jury met a number of times after the two-day event to discuss all of the evidence and write up their findings.

About the language we have chosen to use

For many years the members of People First (Scotland) have said that we prefer the terms "learning difficulty" and "learning difficulties". We believe that they are less stigmatising and more accurate.

In this report when we use the words "people with a learning difficulty" or "people with learning difficulties" we are talking about those people that Scottish law and guidance calls people with a "learning disability" or "learning disabilities".

Where we are quoting from a report or a law and it uses the term "learning disability" or "learning disabilities" we have not changed it.

The questions we decided to look at

The People First Committee talked about the things that we thought were most important to people with learning difficulties in Scotland. We then agreed on the questions we would research and ask witnesses. The questions were all about the Human Rights of people with learning difficulties.

The main questions were:

1. Why are people with learning difficulties not prepared for work and adult life through the education system like other people are; and why is it so difficult to get into the world of work?
2. Why are people with learning difficulties much more likely to be victims of crimes in everyday life; why are we still much too often subject to inhuman and degrading and abusive treatment in care settings and why do we receive much poorer health care from the NHS than the rest of the population?
3. Why isn't the law equally applied to people with learning difficulties and other people? Why is it that people with learning difficulties are more likely to be detained for much longer than other people if we break the law? Why are we more likely to have much more harsh restrictions through Multi-Agency Public Protection Arrangements or Sexual Offences Prevention Orders than people who commit much more serious crimes and who are much more likely to re-offend?



Question 1

Why are we poorly prepared for adult life and excluded from the world of work?

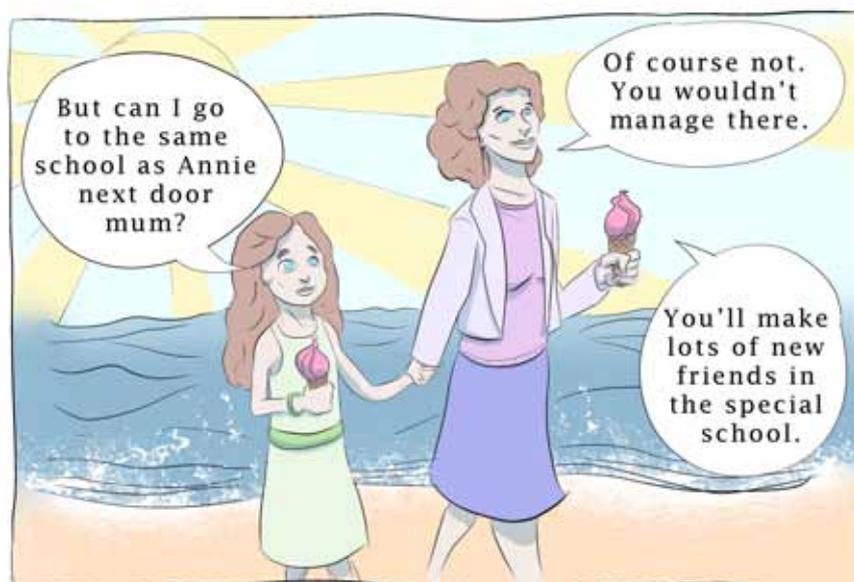
What we know about school and college and how it helps prepare us for adult life

The Scottish Government says it wants to end segregation and separation and bring all children into mainstream schools.

Yet in Scotland at the moment there are 6,800 pupils in 163 special schools.

Children with the most severe learning difficulties are being kept apart in greater numbers in the special school system.

The Jury heard from several witnesses about their experiences of school and college. We were disappointed to hear about the lack of choice that some people with learning difficulties had experienced. Some people had to go to special school even though they would rather have gone to mainstream school.



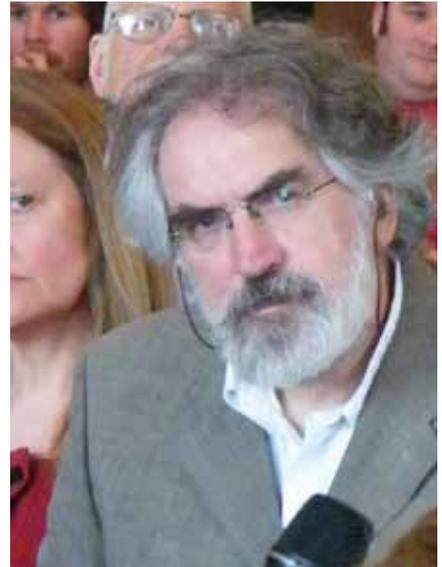
Even people who did attend mainstream school faced difficulties. One person was bullied so much she had to move to another school. The Jury was concerned to hear that she had told her teachers but they didn't do anything.

The Jury was pleased to hear that the parents who spoke believed strongly that inclusion was a right:

“It never occurred to us that she should be in anything other than mainstream school. She’s a part of our family, she fully participates in everything in our family, so why wouldn’t she participate in society fully, that’s the way we see it.”



Gerda Stevenson, Parent



Gerry Mulgrew, Parent

But even in the mainstream school people were dealt with differently from other students. One student had always travelled to Primary School by bus but the High School assumed she would go to school in a taxi with other children who had learning difficulties.

The parents thought that most teachers meant well but said that schools were like factories:

“Some people can’t fit in to those factories; they can’t go at the right speed, they can’t access or get from one classroom to another classroom in the right amount of time so they have to leave one class early, missing some of that class, and sometimes arrive late.”

On the plus side, the Jury was not surprised to hear about the positive contribution that students with learning difficulties made to the life of the school. One head teacher said he had learned more from the student than he had taught.



Overall, the bad things outweighed the good things however. The two parents who gave evidence argued that the whole education system needed to change:

“Inclusion’s not just about being allowed to watch a game you can’t play - you have to change the game, change the rules of the game!”

The Jury also heard of one person’s experience of College. The staff said that the practical work would be easy but the written work would be difficult, and that:

“They wouldn’t provide any support.... they didn’t have any money to support me.”

The Jury believes that colleges do not offer people with learning difficulties access to the kind of courses that will get them proper qualifications and real jobs. People tend to spend a long time at college and yet leave with less qualifications than other students.

Teacher said I could definitely get into the fire service and be a Fireman!



The advisor said that with my grades I could probably study physics at University one day!



Nobody even asked me...



The Jury's findings on why we are poorly prepared for adult life

- People with learning difficulties are disadvantaged by segregated "special" schooling.
- In mainstream schooling, there is not a proper inclusion approach - people are still left to follow what they can and are often excluded from significant parts of the school experience.
- Integration - allowing disabled children to be there but not change anything to take account of their differences - is more common than full inclusion and schools seem to be unable or unwilling to adjust what they do to meet the needs of different people.
- During school, there seems to be very little attention paid to what students with learning difficulties might expect from adult life and they are still being prepared for a life for "different and disabled" people rather than fully human adult lives like other citizens.
- The Government uses parental rights and choice as an excuse for special schools still being the first choice. This is because it is still seen as the "safer" option where children with learning difficulties will be less likely to be bullied and frightened and nothing will have to change in ordinary schools for teachers and other students.
- Guidance and advice given by other professionals adds to the parents' worries and influences their decisions.
- For children with learning difficulties, "transition" appears to be about the move from child services to adult services rather than from school to work as other students expect.

Based on these findings the Jury makes the following Recommendations:

1. Getting education in mainstream schools should be a right - parents' choices should be made within the mainstream system like everybody else.
2. Extra support should be available in mainstream schools as the Additional Support for Learning Act says.
3. Government and local authorities should take responsibility to make sure that all schools are safe places for all children to be.
4. The "transition years" - coming to the end of time at school - should pay most of the attention to preparing people for full adult life including paid work and not planning to move people into segregated adult services.



Tammy Clark, People First



David Lednar – People First

What we know about the experience that people with learning difficulties have with work

Nearly 90% of people with learning difficulties are unemployed compared with less than 10% of the general population.

As many as 60% of people with learning difficulties say that they want to work.

Almost half of disabled people as a whole are in work, but only 1 in 10 people with a learning difficulty has a job. This is wrong and we can't wait for better economic times to do something about it.

The barriers to employment include a lack of training and education, a lack of support, the welfare system itself, the attitudes of employers, and straightforward discrimination.

The Jury heard evidence that education and employment opportunities for people with learning difficulties are simply not good enough. Having a job is a necessity for most people, yet the majority of people with learning difficulties have little real experience of work:

“I am 32 years old and I have never had a paid job in my life. I feel really angry and hurt about this. I am so willing to work but no one has ever given me the chance. This is because of the stigma that surrounds having a learning disability.”

The Jury heard that employers can be prejudiced against taking on people with learning difficulties. They sometimes worry about what staff and customers would think and were worried that employees with learning difficulties would be less productive and off sick more than other employees.

The Jury heard that even if jobs are available, the complicated benefits system doesn't help people to move into paid work. Pressure is often put on people by professionals telling them

that they will lose out financially if they take a paid job. Voluntary work placements are poor substitutes and rarely lead to a job.



OR...



One strange thing the Jury looked at was the difference between Incapacity Benefit and Income Support (for reasons of disability). To receive Incapacity Benefit, you must have paid National Insurance contributions in the past. This means that you must have worked for a wage at some time in the past before being eligible for benefits. Most people with learning difficulties won't have paid National Insurance Contributions because they've never had a job. Because of that, they are more likely to be put onto Income Support for reasons of disability.

Being on Income Support means that you are not able to get the Supported Permitted Work earnings. Only people on Incapacity Benefit can qualify for that. People on Income Support can only earn the Permitted Work Lower limit of £20 before their benefits are affected. The Jury found this was direct discrimination against people with learning difficulties.



Michael Stirling, People First



Ivan Cohen, People First

One person told the Jury about the positive benefits of using a job coaching service both to find and to hold down a job. In addition, two witnesses reminded the Jury that having a job helps build emotional security and confidence. Work is also one of the main places we make friends:

“It is good to get paid but I also like getting to know new people.”

The Jury read about Marc Gold’s Try Another Way approach from the nineteen sixties and seventies which had great success in supporting people with very high support needs to manage paid work. The Jury was convinced that with the right help and support, everyone could benefit.

As one witness said:

“I have had the pleasure over the years to get to know hundreds of people who have proven their employment worth and I know that, with the right help and support, employment can be a reality for all”.



Norma Curran, Values Into Action (Scotland)

The Jury's findings on why we are excluded from the world of work

- People with learning difficulties are much less likely to be in real paid employment than other citizens.
- The benefits system is still a barrier to people with learning difficulties, especially the difference between Incapacity Benefit and Income Support (for reasons of disability).
- Negative public attitudes towards people with learning difficulties are also present in employers and in Trades Unions, making it very difficult for them to be accepted as employees.

Based on these findings the Jury makes the following Recommendations:

5. The benefits system must be made easier to understand and work through and it must allow people to be paid for work.
6. Schools, colleges, and work places should encourage the inclusion of people with learning difficulties to be seen as a positive thing, contributing to the experience and learning of everyone else rather than as a bother and a nuisance and a distraction from "real" work and "real" education.
7. An unacceptable number of people with learning difficulties are not in work and that should change. Public sector employers should set an example and a standard by employing more people with learning difficulties.
8. Supported employment services should be available to all people with learning difficulties. The Scottish Government should put pressure on local authorities to make good quality supported employment services available.
9. Agencies that call themselves supported employment agencies need to make sure that people get real paid jobs - voluntary work experience is not supported employment!



Years Later...



Question 2

*Why is it ok to treat us so badly
...in the NHS?
...in care settings?
...on the street?*

What we know about the experience that people with learning difficulties have in the NHS

The health statistics for people with learning difficulties are devastating:

People with a learning disability are 58 times more likely to die before the age of 50 than other citizens.

46% of doctors and 37% of nurses say that people with learning difficulties receive poorer health care than other people.

35% of health workers reported that they had not been trained in making adjustments to support people with learning difficulties.

70% of GPs receive no training to help them treat people with a learning disability, and 90% felt that a person's learning disability made it more difficult to make a diagnosis.

The Minister for Public Health told the Jury that she knew that people with learning difficulties get a poorer quality of health care from the NHS than other people.

She talked about Jimmy Mauchland, a man with learning difficulties who died in hospital in Dundee in 1999. There was a Fatal Accident Enquiry that looked into why he did not get the care he should have. Their report said that staff had not looked at what Jimmy's health requirements were.

The Enquiry Report said that poor communication had been a cause of the problem. The Jury heard that many of the complaints about the NHS are about poor communication. Staff training is part of the solution - but so is simply listening and speaking to the families.

The Jury heard from People First members who had also had bad experiences in the NHS.

“I asked the nurse for a drink of water and she turned to another nurse and said I don’t understand what that guy is saying. She did not take the time to listen to me.



At night I was not able to push the call button - I couldn’t reach it. I shouted for help during the night but there was no reply - the nurses did not hear me. I had to lie in pain. I felt quite anxious and scared. Throughout my 4 days I was not offered a bath or a shower. In fact my PA provided my personal care. She had to do this at visiting time. On leaving, the nurse insisted they did not have the facilities and staff to provide this personal care. They said the PA should have provided the care at all times while I was in hospital.”

There have been recommendations for changes that are intended to make things better in the NHS. These included a recommendation that each hospital should have a learning disability liaison nurse. This person’s job would be to look out for the interests of any hospital patient with learning difficulties. They must make sure that other staff know basic things about the person, ensure the family are involved and so on. The Jury was not convinced that specialists like this are needed.

People with learning difficulties would rather have good care and treatment from every nurse and doctor rather than wait for someone specially trained. Having specialists like this can make other doctors and nurses feel that it is not their job to understand or provide care for people with learning difficulties. The Jury also did not understand why doctors should be paid extra to give longer appointments to people with learning difficulties. Jury members felt strongly that everyone should have enough time to explain their health problems and doctors should always take the time to understand and give proper treatment.



The Minister told the Jury that after hearing the evidence it was clear to her that there are still problems and that the NHS is not getting it right every time. She accepted that the Government needs to do more.



Shona Robison MSP, Scottish Government

The Jury's findings on why we are treated so badly in the NHS

- People with learning difficulties clearly get worse health care than other citizens.
- This is not because they are less healthy or do not look after themselves or have hugely different health problems.
- It is because medical professionals are either not able to see people with learning difficulties as ordinary patients or because they lack the skills of communication to make better diagnoses and offer better treatment.

Based on these findings the Jury makes the following Recommendations:

10. It is unacceptable that people with learning difficulties have poorer health care than anybody else. The Government should make sure that there is better communication training for all health professionals.
11. The NHS should stop making additional payments to GPs for meeting people with learning disabilities in surgeries and, instead, expect good diagnoses and treatments for all people, regardless of difference.



Edward Stanton,
People First



Kenny Steadwood, People First

What we know about the experience that people with learning difficulties have in care

Care settings are not always safe places for people with learning difficulties.

There is so much evidence on the sexual abuse of people with learning difficulties in institutional and other care services that many specialist organisations (for example: The Ann Craft Trust, Voice UK and Respond) have had to be formed to draw the public's attention to this disgrace and to try to expose the abuses.

It is clear that abuse is widespread. Sex offenders consider people with a learning disability to be an easy target because they are vulnerable and they may be reluctant to bring cases against their abusers.

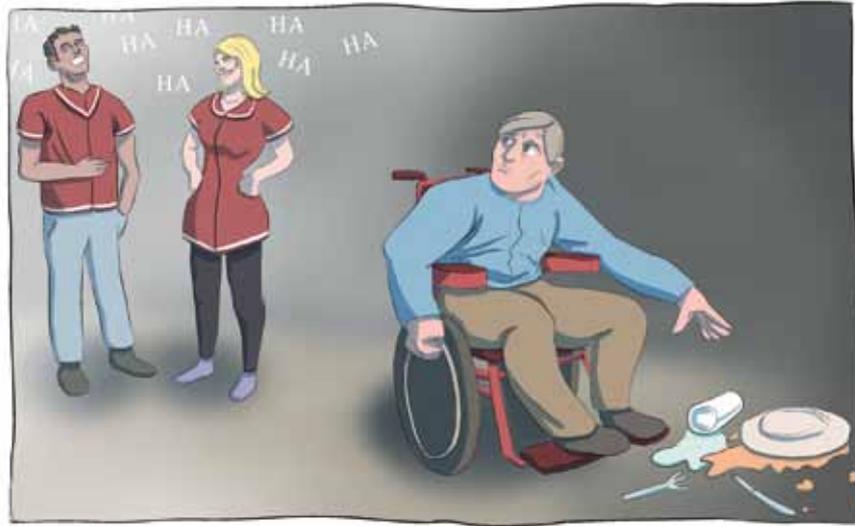
Abusers are mainly male and are generally known to the victim. Of particular concern are the cases in which the abuser is a person in a position of trust, power or authority who takes advantage of that position in order to abuse.

There have also been several scandals in institutions and other care services where people have been bullied and physically abused by care staff.

The Jury heard that abuse, in different forms, still happens in some care settings. One anonymous witness told the Jury about her life in a group home. She said:

*"It's not a nice place... it's the staff. Some of them are alright but *** is rude to me. He won't help me with my book. He sends me to my room. He said he would lock me in. I was worried he gave *** a cold shower but she said he never but I don't know. I spoke to *** the manager but she said I just try to get people in trouble. I get frightened if he's on shift. I think he doesn't like me."*

Witnesses suggested that there are some things that can be done to reduce the risk of abuse in care settings: making sure that services are really person centred and well connected to the local community. As well as the system at the moment where staff backgrounds are checked and police checks done - references should always be taken up. There must also be good training, good support and regular supervision.



It was suggested to the Jury that services must always be monitored, internally and externally so that problems are actually picked up. The government believes that a strong external inspection and regulation system helps prevent abuse in services.



Marcia Ramsay, Care Commission

As with the NHS, the Jury was convinced that services need to listen more to what people say - to listen and explore and understand and to take what people say seriously. If staff stop listening, people will stop speaking up.

The Jury heard evidence from research that the way staff treat people often reflects the way that staff are treated themselves. If staff are on low pay, unqualified and treated badly, they are more likely to treat the people they care for in a bad way. If care staff live in a society where people with learning difficulties are seen as not worth anything, they will probably reflect those attitudes in their work.



Ms C., anonymous witness. Filmed evidence

The Jury's findings on why we are treated so badly in care

- People with learning difficulties are more likely than other vulnerable people to be harmed by care workers.
- They are also more likely to be harmed by care workers than anyone else.
- That's not because care workers are evil. It's because care settings are where people are grouped together. It is then easy to lose sight of the fact that this is an individual human being with a personality and with needs and, instead, see the person as "one of them".
- The result is that people stop getting treated as human beings.
- Abuse and mistreatment in care settings is a reflection of wider social attitudes towards people with learning difficulties.

Based on these findings the Jury makes the following Recommendations:

12. Commissioners and providers should work together to create a career structure and reasonable pay structure for care staff so that supporting people with learning difficulties is a valued and attractive career.
13. The Care Commission, the Mental Welfare Commission Scotland, any new inspection organisations and other scrutiny bodies should be required to keep up unannounced visits.
14. Group care settings should be the last possible option to be considered for people. When it does happen, it should be safe and well managed and supervised so that it is individualised, person-centred and helps people achieve their personal outcomes.

What we know about the experience that people with learning difficulties have with prejudice and crime on the street

Nine out of ten people with a learning disability have been bullied in some way in the last year.

Forty seven percent (47%) have been frightened or attacked because of their learning disability.

People with learning difficulties are four times more likely to experience sexual violence or sexual abuse.

They are four times more likely to have their property stolen.

They are twice as likely to be burgled.

Like the health service statistics, these are devastating figures.



The Jury heard of targeted harassment and abuse of people with learning difficulties in the community. One witness described his experiences:

“When we moved out of Gogarburn to Leith we got a flat. People were moved from another area to new flats that were built across the street from me and that’s when it all started. Children broke my windows and broke my roof slates. My wife couldn’t stand it any longer so we contacted the police. But the police said they couldn’t do anything to catch them.”



Jimmy McIntosh, Disability activist

The President of the Association of Chief Police Officers in Scotland (ACPOS) agreed that the crime figures he had heard were devastating. It was not acceptable that people with learning difficulties are so discriminated against. He said that police training would have to get better. At the moment police officers are not trained to recognise someone with a learning difficulty and to communicate properly. He wanted to improve the way they work with people with learning difficulties out there on the street or in their homes.

He accepted that there are many incidents that are not reported and that the police only see the tip of the iceberg. He wanted to find ways for the police to get in early to prevent discrimination.



The Jury heard about the new Offences Aggravated by Prejudice Scotland Act which is sometimes called Hate Crime. This new law says that if you commit a crime against a person with learning difficulties, because they have learning difficulties, it is treated as a more serious crime. However the Jury were concerned that unless someone actually shouts or writes down that they have picked their victim because they have a learning difficulty, and that this alone is the reason they are committing the crime, then it is very difficult to prove this is a "hate crime".

The Jury was pleased that the President of ACPOS was able to give a commitment that the police would look at the need to be tighter about counting and documenting all crimes against people with learning difficulties not just those that are aggravated by prejudice and those that result in convictions.



Pat Shearer, Association of Chief Police Officers in Scotland

The Jury's findings on why we are treated so badly on the street

- People with learning difficulties are much more at risk from crime of all sorts - assaults, robbery, theft, sexual offences, mugging, than other people. This is unacceptable.

Based on these findings the Jury makes the following Recommendations:

15. All crimes against vulnerable people should be recorded by the police and courts even if active prejudice cannot be proved.
16. There should be programmes to tackle issues of prejudice, discrimination and equalities amongst young people generally, and particularly with people identified at higher risk of offending.
17. ACPOS and People First (Scotland) should work together to make sure that police training prepares officers to work supportively with people with learning difficulties in the community.

Question 3

Why don't we have the same Human Rights as other people?

Why don't we have the same Human Rights as other people?

The Human Rights of people with learning difficulties in Scotland are breached - withheld and denied to people - in at least three different ways:

The right to liberty and security: this is breached when unnecessary restrictions are imposed on people with learning difficulties if they're caught up in the criminal justice system.

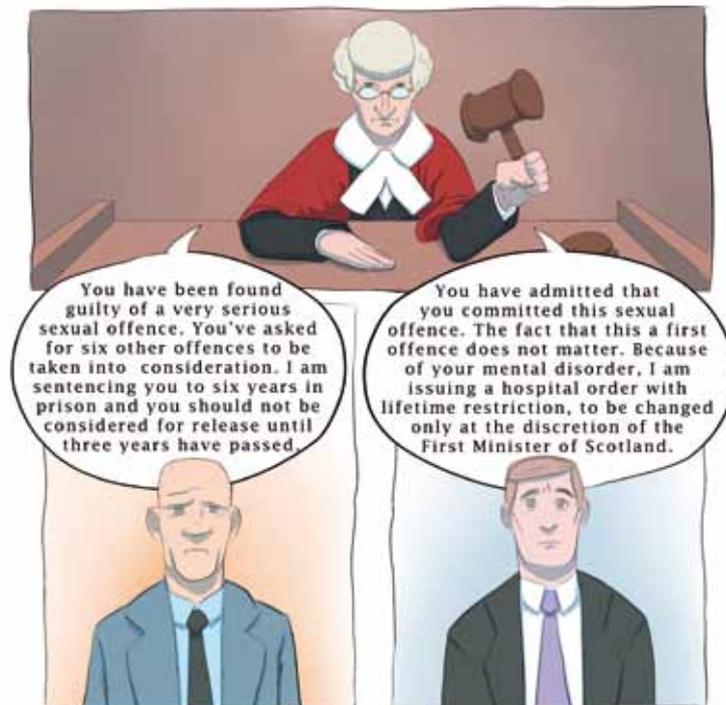
The right to a fair trial: people with learning difficulties often don't get a trial at all. The right is breached in "examinations of fact" where they are simply handed over to medical professionals and taken out of the criminal justice system.

The right to freedom of association: this is breached when people are not allowed to go to some places because others have decided that they may not do so.

Some, but not all, professional witnesses agreed that people with a learning difficulty are disadvantaged when they come into contact with the criminal justice system. The Appropriate Adults Scheme is supposed to help with communication and to protect the person's rights. However many people with learning difficulties think that it is more help to the police than to them. The Jury found that even when people had access to an Appropriate Adult it was very difficult for people to have their voice heard.

People First believes that people with learning difficulties are treated differently to other offenders and have greater restrictions placed on them. Most of the professional witnesses did not agree with this. However, the Jury was convinced that compared with other offenders, people with learning difficulties have greater restrictions put on their lives.

The Jury heard that up until 1995, in Scotland, if you were said to be "unfit to plead," then you could be sent off on a hospital order if you had been charged with a serious offence. The evidence was never gone over in court. In 1995 the law brought in what is called an "examination of fact". This is a bit like a trial where the judge has to be convinced beyond reasonable doubt, that the individual did the thing that they were accused of. The Jury agreed this was an improvement and that it was "like a trial" but not the same as a fair trial.



People first heard evidence from a man with a learning difficulty who had a Sexual Offences Prevention Order which seemed to be much more restrictive than anyone else would have got for a similar offence.

The Jury accepted that the wider community has a right to be protected from sexual offences but on the other hand, everyone has the right to liberty and this man's freedom was restricted more than other similar offenders who did not have learning difficulties.

The Jury was worried that the Scottish Human Rights Commission does not have the power to look at individual human rights cases. There does not seem to be a straightforward way for people to challenge the restriction on their lives.



Lindsay Thomson, Medical Director
The State Hospital

Several professional witnesses told the Jury that these kinds of orders were necessary because prisons are a very unhealthy environment and can be very risky, dangerous places for people with learning difficulties. People can find themselves much more vulnerable to being bullied and to being mistreated. The idea of sending people with learning difficulties who commit offences to hospitals instead of prison was meant to be protective and to be helpful. However some people end up trapped in legal orders and in specialist health services from which there is no easy way out.



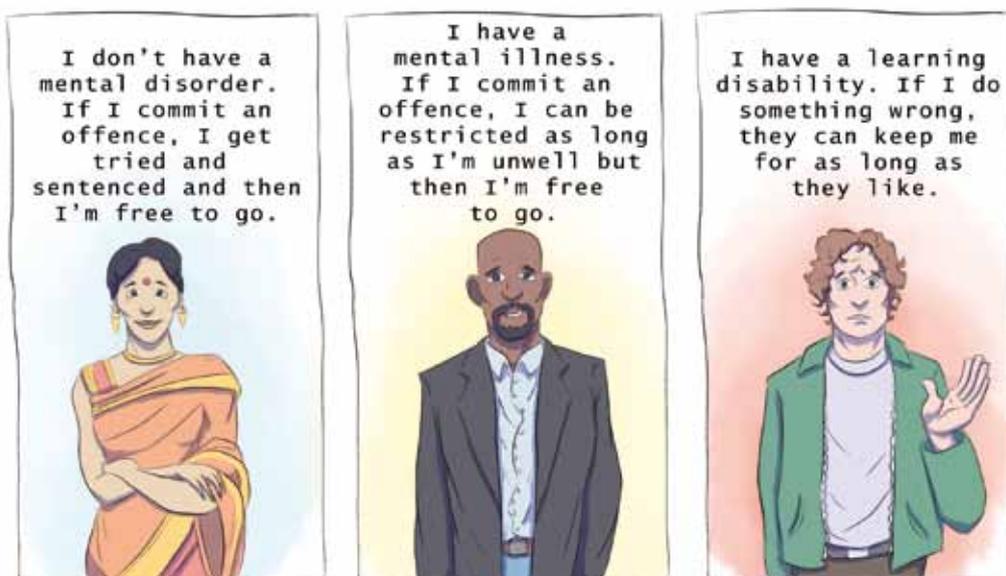
Susan Hunter, Honorary Fellow,
Social Work, Edinburgh University

One witness told the Jury:

“My lawyer says I need an independent psychiatrist’s report to say I won’t hurt anyone. I got one but he said he couldn’t say I would never hurt someone. I never hurt anyone in the last 29 years but he said that might be because I never had the chance to do it.”

“They should give me a chance to get out. A chance to get a life because I’ve never had one. I don’t think it’s fair. It’s like locking you up and throwing away the key.”

All of the Jury members agreed that the law needs to be changed to make it clear that mental ill health and learning disability are different and should not be lumped together under the label of “mental disorder”. The Jury was also concerned that the Act is designed for people who can be treated and make a recovery rather than for people who have a life long condition that they would not recover from. The professional witnesses had different opinions about this. The Jury heard from two witnesses who thought that a wide definition of mental disorder that included various mental illnesses as well as learning disability was helpful. They said they supported the current Mental Health Act because it is based on human rights, it supports the idea of social inclusion and it provides strong support for advocacy.



Another witness disagreed and thought that the law should change. Even though the 2003 Act has a number of positive features including protection of rights and advocacy, it still includes learning disability in its definition of a mental disorder and so needs to be changed.

The Jury supported the idea put forward in the Millan Review of the 1984 Mental Health Act that a separate law for people with learning difficulties should be considered. One of the witnesses argued that it was more important to improve existing services rather than trying to change the law.

Several professional witnesses spoke to the Jury about Human Rights. They agreed we all have human rights regardless of disability or belief or colour of skin or any other differences. We don't all have the same experiences of getting those rights though. Some people face barriers to getting their rights because of their situation or because of their identity.

Some human rights cannot be taken away in any circumstances. These are called "absolute rights". For example we all have the right to be free from serious ill treatment whether that's physical ill treatment, whether it's neglect or sexual abuse or other forms of serious ill treatment. There are certain other rights that are not absolute. They are known as "qualified rights". Whenever someone's rights are going to be restricted, the following questions must be asked:

- Is there a legal basis for this? This does not mean there has to be a court order - it means there has to be a law that provides a power for someone to limit that right. It might be Mental Health Law; it might be Adult Protection Law.
- Why is it being done?
- Are restrictions as serious as these needed because of how dangerous the person is? If the person is not a serious risk to others, why are these kinds of restrictions being put in place?

If a person's rights are restricted, they should be told why, given the reason and then have an opportunity to challenge that decision and to have it reviewed.



Donny Lyons, Mental Welfare Commission Scotland

The Jury heard reports of situations where people with learning difficulties had been detained or restricted in where they could go and yet there had been no legal basis for those restrictions. They did not understand the restrictions and did not know how they could challenge the restrictions.

For example, in a case written about by the Mental Welfare Commission, Ms A was a woman with learning difficulties who was sexually abused. She reported 12 instances of sexual abuse and rape over a seven-year period and yet nobody was ever prosecuted for it. The Mental Welfare Commission was concerned that the local authority social workers were confining her to her own house. She was only allowed to go out if there was somebody with her. This loss of freedom was a serious restriction but the social workers had not applied for guardianship through the courts.

The Jury was concerned that watchdog organisations like the Mental Welfare Commission and the Scottish Human Rights Commission have limited powers to challenge the power of

professionals in such situations. We were also worried that Mental Health Tribunals too often simply agree with the medical opinions that are given to them. While the Jury welcomed the Commission's suggestion that Tribunals give people their say at a much earlier stage, we felt this did not go far enough in helping people challenge medical opinion.

The Jury was very concerned that most solicitors who represent people with learning difficulties at Tribunals or court are too ready to accept medical opinion. We think they should have to present legal arguments about the person's situation. These should be based on the principles of the Mental Health Act. The solicitors should then put up an independent proposal about any restrictions. If a restriction is suggested it should be their job to make sure that it is not too severe for the kind of risk that the person has presented.

The difficult task of balancing rights and risks was raised several times. The Jury agreed that we should always presume that people with learning difficulties are capable of making decisions about their own life, and we should give support to help people make informed decisions. Sometimes, however, there will be a need for the state to protect people from the risk of harm.

The United Nations Convention on the Rights of Persons with Disabilities applies to everyone who has a long-term physical or mental or intellectual disability. It is the job of the Scottish Human Rights Commission to find out about the barriers that stop people with learning difficulties getting their rights and to help overcome or get rid of them. The Jury was pleased to hear that the government supports most of the United Nations Convention on the Rights of Persons with Disabilities. However we were still concerned that the Scottish Human Rights Commission does not fully understand the daily experiences of people with learning difficulties and wholeheartedly welcomed the opportunity for People First (Scotland) to work with the Commission on these issues.

The Jury believes that people with learning difficulties must be recognised as equal citizens under the law. It is far too easy for men and women with learning difficulties to be treated as though they are not really equal adult citizens. There is a prejudice in society and in the general public that must be challenged.

The Jury supported the idea that People First (Scotland) and the Government could run a campaign similar to the See Me campaign on mental illness and stigma. This could help the general public understand and accept that people with learning difficulties are full and equal citizens.



Duncan Wilson, Scottish Human Rights Commission

The basic law of the country says that once you reach the age of 16, you are as much an adult as anyone else, no matter what kind of disability or label you have. As far as the law is concerned, you only stop being an equal adult citizen if someone is appointed as your guardian. Thankfully, very few people in this country are under guardianship orders. The Jury was wary and cautious about this. We have heard of some countries where most people with learning difficulties, regardless of how able they are, have court-appointed

guardians to make decisions for them. Some of the Jury had met French people who were very able indeed but were not allowed to make any choices for themselves. The Jury was worried that some families or social workers might be too quick to apply for guardianship orders just so they could not be blamed for preventing the person from making their own decisions.

Many adults with learning difficulties still get treated as if they are children. Some professionals behave as though they have powers over people with learning difficulties that they do not actually have. The Jury agreed that advocates are needed to help challenge such behaviour.

Of course there are times when people do need extra protection. There are others out there who may want to exploit the person and the person with learning difficulties might not always understand what the risks are. This does not give social workers or anyone else the right to use the extra protection laws to treat someone with learning difficulties as a child or as a pretend adult. These laws are supposed to be used to make sure people get extra protection when they need it - but not control them when they don't need it.



John Dalrymple, Neighbourhood Networks

The Jury's findings on why we don't have the same rights as other people

- People with learning difficulties who offend do so for the same reasons as other people. The only additional factors are sometimes people with learning difficulties have had less opportunity to learn about what is acceptable or what's a healthy expression of sexuality. In relation to violence, sometimes people with learning difficulties may not have learned to control their impulses or their emotions but also sometimes people are treated with such disregard, with lack of dignity, sometimes with mistreatment so that spontaneous violence sometimes does occur.
- People with learning difficulties are detained for longer and have greater restrictions placed on them than other people who commit higher levels of offence.
- Very often, the length and nature of restrictions and detention are out of proportion to the offence that has been committed and are exaggerated by ideas about mental disorder.
- The main laws governing the detention and treatment of people with learning difficulties are the Criminal Procedures Act 1995 and the Mental Health (Care and Treatment) Act 2003. These laws are designed for people with a recoverable mental health condition rather than for people who are intellectually impaired. People with learning difficulties are treated as if they have a disorder of thinking or judgment or reasoning as opposed to needing a longer time to understand and work things out.
- Current application of the Criminal Procedures Act and the Mental Health Care and Treatment Act are not in line with Human Rights laws.
- There should be programmes designed to help the wider community see people with learning difficulties as citizens, adult human beings with the same rights and hopes and dreams as everyone else.
- It should be clear who has the allocated responsibility for any programmes intended to tackle negative attitudes to people with learning difficulties.

Based on these findings the Jury makes the following Recommendations:

18. People First (Scotland) should work with the Scottish Human Rights Commission to review the evidence about whether people with learning difficulties have excessive restrictions imposed on them.
19. The Mental Health (Care and Treatment) (Scotland) Act 2003 should be changed to redefine mental disorder and exclude learning disability as a mental disorder. People with a learning disability who develop mental health problems (mental illness) or dementia or acquired brain injury or alcohol related brain injury could be treated under the Act because of their additional condition but not only because of their intellectual impairment.
20. A new law, covering intellectual impairment, capacity and offending by people with intellectual impairment should be drafted.
21. People First (Scotland) should work with the Mental Health Division of Scottish Government to work on an anti- stigma campaign with the same idea and the same kind of money as the See Me campaign.
22. People First (Scotland) should be involved with the Law Society and the Mental Health Division of Scottish Government on a review of Welfare Guardianship.
23. Solicitors who are representing a person with learning difficulties at Tribunals should understand that they must take instructions from that person and represent their interests in the same way they would do with any other citizen. People First and the Law Society of Scotland should work together to produce guidance for solicitors working with people with learning difficulties who appear at Mental Health Tribunals.

Richard Holloway's summing up



Richard Holloway, Questioner for Citizens' Grand Jury

There are good laws that are there to protect all of us but they don't do as good a job of protecting people with learning difficulties as they do the rest of the population.

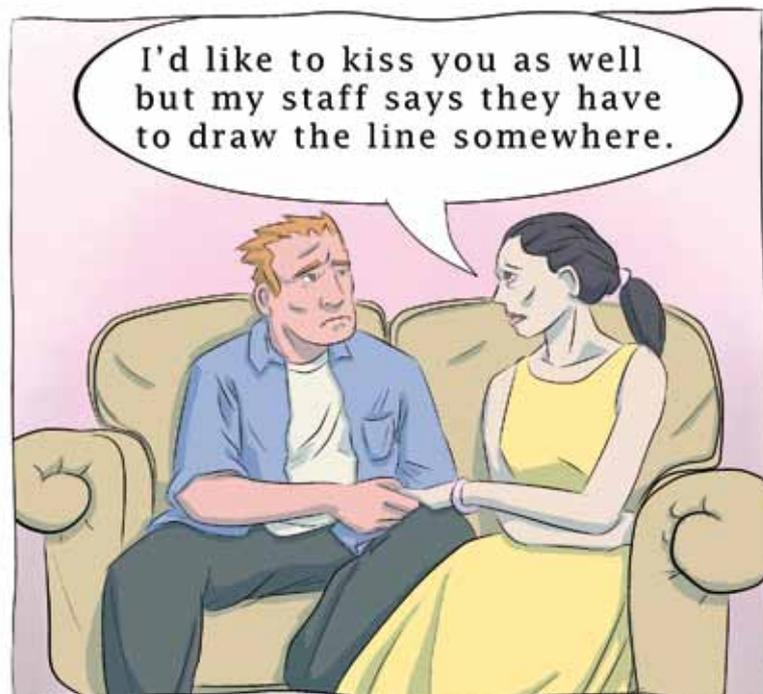
We need to educate the personnel within the Health Service in a way that helps them to work with people with learning difficulties justly, that respects their human rights. The NHS must understand that they may not always be as good at expressing their condition as others; they need patience, they need to translate, they need to adjust.

Care services are meant to be places that protect and enable people to be safe and to grow and to have joyful and happy lives. In fact for many people they have become places of terror and fear.

It can be terrible on the streets, there's a lot of bullying, and a lot of crime is done against people with learning difficulties. We didn't get the impression that the police are complacent about this. They wanted to listen, they wanted to be better at helping people with learning difficulties and I know that People First help them with their programmes. This is a door that is open - there's a lot of improvement that has to be made but I think there is a will to do it.

We noted that the expert witnesses included people who want our society to be a good society. Some of them were a bit defensive about the institutions that they run, and were a bit defensive when they were challenged. We have to get these institutions, which are the instruments of the law, to see that they do not operate equally.

The non-learning difficulties community seems to feel embarrassment about the thought of people with learning difficulties having sex. They think that somehow people with learning difficulties should be asexual. It's as if the other, bigger community wishes that people with learning difficulties didn't have sexual hormones at all. But people with learning difficulties are human like the rest of us.



We are a democracy. We are the government of this country. We may delegate it to politicians to do it on our behalf but it's done for us. This is our country. It doesn't belong to professionals or to politicians or policemen or to doctors or psychiatrists. It belongs to us. They are our servants. On the whole, the laws in this country are skewed against people with learning difficulties.

We are still stuck psychologically in an old way of looking at the world that says:

"These people are different. They can't and don't deserve to be included. They need looked after; Doctors and specialist professionals are the ones to consult, not them. They're not really fully adult human beings."

This is a nightmare for many people with learning difficulties. More than that - it is a moral outrage. It must change!

What we think needs to happen

A summary of the recommendations of the Citizens' Grand Jury

1. Getting education in mainstream schools should be a right - parents' choices should be made within the mainstream system like everybody else.
2. Extra support should be available in mainstream schools as the Additional Support for Learning Act says.
3. Government and local authorities should take responsibility to make sure that all schools are safe places for all children to be.
4. The "transition years" - coming to the end of time at school - should pay most of the attention to preparing people for full adult life including paid work and not planning to move people into segregated adult services.
5. The benefits system must be made easier to understand and work through and it must allow people to be paid for work.
6. Schools, colleges, and work places should encourage the inclusion of people with learning difficulties to be seen as a positive thing, contributing to the experience and learning of everyone else rather than as a bother and a nuisance and a distraction from "real" work and "real" education.
7. An unacceptable number of people with learning difficulties are not in work and that should change. Public sector employers should set an example and a standard by employing more people with learning difficulties.
8. Supported employment services should be available to all people with learning difficulties. The Scottish Government should put pressure on local authorities to make good quality supported employment services available.

9. Agencies that call themselves supported employment agencies need to make sure that people get real paid jobs - voluntary work experience is not supported employment!
10. It is unacceptable that people with learning difficulties have poorer health care than anybody else. The Government should make sure that there is better communication training for all health professionals
11. The NHS should stop making additional payments to GPs for meeting people with learning disabilities in surgeries and, instead, expect good diagnoses and treatments for all people, regardless of difference.
12. Commissioners and providers should work together to create a career structure and reasonable pay structure for care staff so that supporting people with learning difficulties is a valued and attractive career.
13. The Care Commission, the Mental Welfare Commission Scotland, any new inspection organisations and other scrutiny bodies should be required to keep up unannounced visits.
14. Group care settings should be the last possible option to be considered for people. When it does happen, it should be safe and well managed and supervised so that it is individualised, person-centred and helps people achieve their personal outcomes.
15. All crimes against vulnerable people should be recorded by the police and courts even if active prejudice cannot be proved.
16. There should be programmes to tackle issues of prejudice, discrimination and equalities amongst young people generally, and particularly with people identified at higher risk of offending.
17. ACPOS and People First (Scotland) should work together to make sure that police training prepares officers to work supportively with people with learning difficulties in the community.

18. People First (Scotland) should work with the Scottish Human Rights Commission to review the evidence about whether people with learning difficulties have excessive restrictions imposed on them.
19. The Mental Health (Care and Treatment) (Scotland) Act 2003 should be changed to redefine mental disorder and exclude learning disability as a mental disorder. People with a learning disability who develop mental health problems (mental illness) or dementia or acquired brain injury or alcohol related brain injury could be treated under the Act because of their additional condition but not only because of their intellectual impairment.
20. A new law, covering intellectual impairment, capacity and offending by people with intellectual impairment should be drafted.
21. People First (Scotland) should work with the Mental Health Division of Scottish Government to work on an anti- stigma campaign with the same idea and the same kind of money as the See Me campaign.
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23. Solicitors who are representing a person with learning difficulties at Tribunals should understand that they must take instructions from that person and represent their interests in the same way they would do with any other citizen. People First and the Law Society of Scotland should work together to produce guidance for solicitors working with people with learning difficulties who appear at Mental Health Tribunals.

Appendix 1 - The Members of the Jury

1. Monica Hunter, Jury Chairperson Board Member, Edinburgh
2. Steve Robertson, Chair Board of People First Scotland
3. Moira Oakley, Board Member, Borders
4. Fiona Wallace, Board Member, Midlothian
5. Pamela Niven, Board Member, Glasgow
6. Billy McLeod, Board Member, Highland
7. Idem Lewis, Board Member, Glasgow
8. Alex Thomson, Board Member, Aberdeenshire
9. Keith Lynch, Board Member, Edinburgh
10. James McNab, Board Member, Fife
11. Katrina Robertson, Board Member, East and West Lothian
12. Brian Scott, Board Member, South Lanarkshire

Appendix 2 - The Witnesses

Witnesses – In order of appearance

Question 1 : Why are we poorly prepared for adult life and excluded from the world of work?

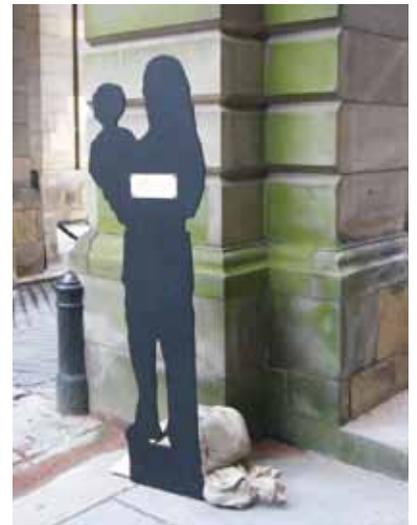
1. Alison Rae, Member People First Scotland
2. Michael Stirling, Member People First Scotland
3. Ivan Cohen, Member People First Scotland
4. Gerry Mulgrew, Parent
5. Gerda Stevenson, Parent
6. Tammy Clark, Member People First Scotland
7. David Ledner, Member People First Scotland
8. Norma Curran, Development Manager, VIAS (Values into Action Scotland)
9. Edward Stanton, Member People First Scotland
10. Kenny Steadwood, Member People First Scotland

Question 2: Why is it OK to treat us so badly?

11. Jimmy McIntosh MBE, Disability Rights Activist
12. Ms C, Member People First Scotland
13. Pat Shearer, President Association of Chief Police Officers in Scotland
14. Marcia Ramsay, Adult Services Development Manager, Care Commission
15. Shona Robison MSP, Minister for Public Health, Scottish Government

Question 3: Why don't we have the same Human Rights as other people?

16. Mr A, Member, People First Scotland
17. Mr B, Member, People First Scotland
18. Prof. Lindsay Thomson, Professor of Forensic Medicine, Edinburgh University
19. Susan Hunter, Senior Lecturer, Department of Social Work, Edinburgh University
20. Duncan Wilson, Head of Strategy and Legal, Scottish Human Rights Commission
21. Geoff Huggins, Head of Mental Health Division, Scottish Government
22. Donny Lyons, Director, Mental Welfare Commission
23. John Dalrymple, Director, Neighbourhood Networks



Silent witnesses. See the full silent witness evidence at: www.peoplefirstscotland.org



May 2011