“The Wheel Always Turns in Circles”

Accessible Report of the ‘A Story to Tell’ Lifestories project

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“Those who cannot remember the past are condemned to repeat it.”

- George Santayana
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The “A Story to Tell” project is the first large-scale life story project in Ireland, and one of the largest in Europe. The project aimed to find out what the experiences were of older people with intellectual disabilities throughout their lives.

We collected the life stories of 22 people with intellectual disabilities, 16 of which agreed to be part of this report. We looked at what they said, and found out the main themes that were spoken about.

From the contents of the stories, the history of people with intellectual disabilities can be seen through people’s own words and experiences.

The project also created an online digital archive of the life stories, in text and video formats. 11 people chose to share their story anonymously online.

We encourage the reader to not just read the quotes contained in this report, but to go to the archive and read or view the stories in their entirety.
About this report

This is the final report of the “A Story to Tell” life stories project that has been running in the National Institute for Intellectual Disabilities, in Trinity College Dublin since 2006.

In this report you will be able to find out:

- **WHO** worked on this project
- **WHY** we started this project
- **WHAT** we did
- **WHO** we spoke to
- **WHERE** they lived
- **WHAT** they said
About this project

Who worked on this project?

Researchers who worked on this project are Prof. Patricia O’Brien, Prof. Dorothy Atkinson, Dr. Carol Hamilton, Zoe Hughes, Ciara Brennan and Grace Kelly.

Lots of other people helped us with this project like the members of the Transfer of Knowledge committee in NIID, other staff like Dr. Darren Chadwick, Dr. Edurne Garcia, Prof. Roy McConkey, and especially the storytellers. We all decided that we don’t use their names in this report.

Why did we start this project?

A lot of people with disabilities have not had a chance to tell the story of their life

Other people have told their stories for them like doctors, family and support staff

Some people want to forget about the bad things that happened to people with disabilities- we think this is a bad thing

People with disabilities have lots to tell us about what life was like years ago

We wanted to make sure that the history of disability would be collected for years to come
Methodology

There were two parts to this project.

1) We collected the stories of older people with intellectual disabilities

2) We built an online website and archive where anyone can go to read the stories, or watch them as video clips

To collect the stories we worked with people in disability services all over the country: We visited Kildare, Laois, Dublin, Tipperary, Roscommon and Waterford
## Collecting the stories

We had a number of steps to do when we collected the stories:

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<tr>
<td>1)</td>
<td>We went to services to see if they were interested in the project</td>
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<td>2)</td>
<td>We spoke to people in those services about the project and explained what we were doing</td>
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<td>3)</td>
<td>The storytellers had to be over 55, and willing and able to tell their story</td>
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<td>4)</td>
<td>We recorded them talking about their life, and whatever they wanted to talk about. We didn’t ask any special questions</td>
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<td>5)</td>
<td>We went away and typed up what they said on a computer, and made it into a story</td>
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<td>6)</td>
<td>We went back to the storytellers and checked that their story was right</td>
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<td>7)</td>
<td>We made their story into a book for them to keep</td>
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Results

To find out what types of things people talked about, researchers in the NIID looked at all the stories and found themes that people talked about. We did this on a large sheet of paper and came up with different ‘codes’.

These is a picture of the way we did the coding. 4 researchers were involved in this coding.
Who did we speak to, and what did they say?

We spoke to 6 men and 16 women

The youngest was 56 and the oldest was in their 80’s

Most people lived in a group home, with the support of staff

Some people lived in houses in the community, and some people lived in houses on the grounds of an old institution
Even though we did not ask people to tell us about specific things, people spoke about the same kinds of things. The things that most people spoke about were:

- Growing up on a farm & Ireland’s past
- Entry to a service
- Institutional living
- Abuse & bullying
- Changes & reflection
- Religion
- Relationships
- Self-advocacy
- Day service, work & education
People spoke about what life was like in Ireland many years ago. They spoke about farming using hand ploughs and making their own milk and cheese. These are the same things other people have spoken about this time in Irish history.

I was born on a farm. Indeed, yeah. We had cows and calves and all that sort of thing. The haymaking and all that sort of thing, making cox, the hay and bringing it with the donkeys.

I made homemade bread over a baker on a hearth fire. The baker was hanging on a crook and I used to put coals over the fire, on the crook, on the baker, with the lid of the baker to take the bread.

I worked fierce hard, feeding them and taking them out in the fields. Like that, taking the cows for milking...I cut corn and bagged it for the mill, got ready for the cattle feed.
People spoke about different kinds of relationships they had had in their lives; with family, friends, staff and others. Only 1 person we spoke to was in a romantic relationship.

(My nephew) gets around to all different countries, and all, no problem. And he’s a great speaker, a few times he’s been on television, and he was on the radio, even. I’m very proud of him.

I used to have great fun with my father. I wish that all dads were like that.

I never met my mum because the nuns didn’t tell me. It’s a bit sad. I don’t mind now like. I would have like to have met my mum, yeah I would definitely. But I’ve seen photos of her and I’m very lucky.
They sent me here. This is the only place they could send me. Here.

My brother said that he wasn’t going to leave me stay at home if he ever got married. That broke my heart. After doing all that work. I said nothing.

I didn’t know where I was! I kinda knew where I was going alright but when I came up I found it very strange.

So anyway, the 1st of December 1965, it was a Wednesday, Barry’s taxi, down in Glenmire in Cork, came along and I think there were a Brother with him, and they brought me down here. So ever since, I’m with the Brothers –still here now all these years.

People have very strong memories of the day they first entered a service. Some people were not told they were moving into an institution. Some people were happy to find a place for themselves. Most people did not have it explained to them why they were there.
People told us a lot about their experiences of living in institutions many years ago. Some people spoke about how little privacy people had, and how you had to do everything with staff. Other people spoke about how they made friends there, and the kind of work they did every day.

There were great big dormitories there (then) the dormitories kind of went and there was little cubicles, like your own little bedroom. There was about 35 of us. You really couldn’t put much, you only had your bed and the wardrobe. You couldn’t get a chair in it was so small.

I was sharing with other ladies. Three, six of us. I didn’t mind sharing a bedroom, you know. We were happy, that kind of thing.

Ya had to say the rosary at 8 o’clock every night and the television would be turned off. From 8 o’clock to half eight was the rosary. And the rosary was said then, you get up, and sit down and watch television again. We’d watched television until about 5 [mins] to 10 and then go to bed. That was the routine.
I may thank me father and mother, God bless them all, and me Father divine - that’s the parish priest- I’m walking from that day to this. That’s a true story.

I like to go to Mass now, it’s nice, and sometimes there’s singing at Mass. I believe in God, alright I do. I know that He’s there, only we can’t see Him.

I’m always holy, since my young days. I used to go to mass every morning.

I went to school with the nuns. I remember Sister M. She was nice, she was never cross.

Some people told us about having a very strong belief in God. Other people told us about living with the religious Orders that used to look after people with disabilities. One lady told us how she believed in God because he healed her and made her able to walk. Some people went to Mass or church regularly.
Some people spoke to us about being abused in the past. This happened in different ways - some people were bullied and called names by other people who lived with them, some people weren't treated properly by the people looking after them, and some people were sexually abused by people in the service or who lived near by.

One of the staff there absolutely abused me, physically and mentally. Name calling, criticising me, laughing at me, smirking dirty, talking about sex, dirty words about sex.

There was a kind of bullying in it. Sometimes they’d bully you for money. Sometimes they’d verbally bully you and some of them would set out to physically harm you... They tried to drown me on three occasions by holding my head under water. I was powerless to resist.

She was a very cruel nun. She locked me in a cupboard and then she locked me in the morgue.

... no matter how I banged at their door. I nearly kicked the doors down. I was looking for help and no one would do anything. They kept saying to me ‘This is not on. You can’t come up complaining about what’s going on.’
Day service, work and education

Some people were happy with their activities, and some weren’t. People spoke about working for no money in the past. People also spoke about not getting the right kind of teaching in school.

See they were trying to make out that they were giving you a few bob out of the goodness of their heart and (that) you were there at their kind of discretion. It wasn’t like where you go to a job and work and get paid by the hour you know. (It was like) they made allowances for you being there. I suppose it was just normal at the time.

Well I like working with the old people. Old people, I like talking to them, I think they’re very interesting, you know? And some of them are very lonely and they like you to talk to them.

I was just able to write me name. I got no learning or nothing, I couldn’t. Never got taught, never got taught. They just, they learned me name and that you know. You do a bit of learning, not much really. Just sums and that, you know?

It was a long time ago, I liked it. I do see my friends from school now.
I was picked to do the rights project. I’m doing quite a lot of things at the moment arising from the rights project. I’ve become a member of Amnesty International and I’ve also joined the Labour Party as well.

I’m trying to get my share of my mother’s will, place. But I don’t think I’m going to get it. It hurt me a lot. I worked hard on the land, same as Jackie and Lucy. It hurt me a lot when I’m not being told anything… The solicitor I have don’t tell me anything, and that’s not fair on me. I am entitled to know, people notice I am not myself. I know they say it very much in work but they know I am not myself I am fighting it, well I am fighting hard with it.

While most people who told us their stories did not describe themselves as a ‘self-advocate’, people told us stories about standing up for their rights. One person told us how she is fighting to get her share of her Mother’s will; another is very involved in a Human Rights project.
Looking back on whatever happened I didn’t really need to be running away at night and sleeping rough. You’re not dealing with the actual sense of reality. Everything is all jumbled up. You’re all confused and you think this is going to chase it all away and it doesn’t chase it all away…

I never got a chance to go out into that big, wide world and get a job, and look for a job, probably get married and (be) having a couple of kids and grandkids by now. I never, never got that chance. I didn’t give it thought often until now.

... But when they come to my age, they’ll all change. They won’t be the same as they are now. So that’s the way, you know? And then I’ll be well gone then— they’ll always remember a fella called John Shaugnessy years ago— like the way I looked at people I remembered years ago. Same thing. The wheel always turns in circles, huh?

People who are older have learned a lot from their experiences of life, and can see how things have changed. People with disabilities are the same as everyone else— they have lots to say about how life is
Conclusions

The things people talked about can tell us a lot about Irish history, and about the way that services have worked in the past for people with intellectual disabilities.

People with disabilities have very clear memories of things that have happened in their lives, things that happened many years ago.

These stories add to the history of Ireland, especially when it comes to everyday experiences of living in an institution.

People have both good and bad memories of living in institutions. People did not have privacy and worked very hard, but they also made good friends.

Some people were abused and treated badly by the people whose job it was to look after them.

People have seen lots of change in services, and are happy about that.
We wanted to make sure that lots of people had a chance to read the stories that people had told us, and that the storytellers could share them with the world. So we built a website that has stories in text and video forms, so that they accessible to as many people as possible.

http://www.tcd.ie/niid/life-stories

OR

www.niidlifestories.tk

The “A Story to Tell” archive is the first of its kind in Ireland and Europe.

11 people wanted to share their stories on the archive
We asked the storytellers who they would like to read their story for the archive. Some people read it themselves, some people asked a friend to do it, or for someone in the NIID to do it.

We recorded that person reading out sections of the story using a microphone.

The researchers then found photographs that showed what the person was talking about.

These photographs were then matched to the recording using a computer program called iMovie. This meant that the story was now a film with words and pictures.

We worked with the Trinity College Web Office to design the archive and make the videos available.
What’s on the archive?

This picture shows the sections on the archive.

There are 9 main sections on the archive. Each section has different information in it. There are sections that give you basic information about the site and the project and the researchers.

The stories are there to be read and watched.

There are sections that tell you information about telling your story, and what you need to do so.

There is a section where people can submit their own story and we can put it up on the archive.

There is a section with links to other archives and websites for people to look at.
The archive is available for anyone to look at.

We have been working with lots of different groups of people about storytelling.

We hear all the time about more people who are interested in storytelling and disability in Ireland.

We hope that people will read the stories for years to come to learn about what life has been like in Ireland for people with intellectual disabilities.

We will keep working with different groups that are doing life story work, and keep the connections with project that we have gathered since we started this project in 2007.

Images in this report courtesy of photosymbols.com and freeimages.co.uk