

'A Story to Tell': learning from the life-stories of older people with intellectual disabilities in Ireland

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Accessible summary

- Older people with intellectual disabilities have been telling their life-stories in Ireland.
- People remember being taken away from their family and community. People talk about sad memories of times in institutions.
- People talk about the kindness of friends and family.
- These stories tell staff that older people want to talk about their past and need help to do this. Doing life-story work will help staff to find out what older people who are in services in Ireland need to make their lives meaningful and comfortable.

Summary

This article draws on life-stories told by older people with intellectual disabilities for a research study in the Republic of Ireland. Research participants recalled their experiences of confinement, coercion and exclusion that resulted from their being labelled as having intellectual disabilities. Participants also recalled the positive interactions with workers and family members that sustained them during these difficult times. Extracts from these narratives show how past medical and social processes interlinked to classify members of this group as 'deficient' or 'lacking' in some way. Life-stories collected in this project illustrate the value of a narrative approach to exploring how services might begin to enhance the quality of support currently provided to older people with intellectual disabilities. However, life-story work in a service setting is far from straightforward, and support is needed for staff involved in this process.

Introduction

Life-stories are people's accounts of their past experiences as told to another person or persons at various points in time (Atkinson et al. 1997). The process of telling their life-stories can be empowering for people with intellectual disabilities (Meininger 2006). In documenting instances of personal resilience and struggle against acts of discrimination and exclusion, life-story work can

contribute towards an understanding of difficult past life events, thereby encouraging an individual's more profound sense of self and identity (Atkinson 2005). Collecting these narratives also acknowledges members of this group as people who have significant experiences to share. Through the recounting of relationships with families, friends and other members of the wider community, life-stories allow people without intellectual disabilities to become aware of the shared, yet often hidden social history which binds the lives of all community members together (Atkinson 2004; Meininger 2006). In this sense, these narratives can be seen as valuable sources of instructive life-experience that can enhance the development of wider community life (Coleman 1986).

Life-stories too are valuable for their ability to make epistemological connections. Life-story work opens up a point of focus beyond the actions of discrete individuals, revealing the network of underlying structures and forces through which the actions of every-day life are constructed (Roets et al. 2008). In particular, in detailing the often thoughtful and reasoned responses people with intellectual disabilities have made to the extremely difficult social circumstances they encountered, these narratives question the notion of 'intellectual disabilities' as an ever-and-always fixed, universal category or position. Thus, collecting and disseminating life-stories presents a compelling challenge to the array of powerful social forces through which those who have been labelled 'intellectually disabled' have come to be regarded as inferior merely 'because of a perceived lack' (Bird 1994, p. 108).

Methodology

The study – the 'A Story to Tell' Life-Story Research Project for People with Intellectual Disabilities – began at the National Institute for Intellectual Disability (NIID), Trinity College, Dublin, in 2007. The initial idea drew on a number of sources including the Royal Albert Hospital Project archive in the UK, the Kew Cottages Oral History Project in Australia (Manning 2008), the Open University Social History of Learning Disability Research Group in the UK and the Online Museum of Disability (see notes for online access details). Ethical approval for the study was obtained in 2007 from the School of Social Work and Social Policy Ethics Committee at Trinity College, Dublin. The project received added momentum from the Irish Research Committee for Health and Social Services (IRCHSS), which funded the collection and archiving of 15 life-stories of people with intellectual disabilities over the age of 60.

Initial participants for the study were obtained through already established contacts associated with the NIID. One participant was contacted after sharing part of his life-story at an anti-bullying workshop held at the NIID in the summer of 2007. The second participant was suggested by an advisor to the 4-year National Survey of People with Intellectual Disabilities being undertaken at the same time. From these beginnings, a small pilot study was undertaken. This consisted of an initial life-story collecting meeting lasting approximately 1 h. Digitally recorded life-stories were transcribed by a researcher and read back to

the participant at a second meeting. An extended discussion with each participant about additions, alterations and deletions to be made to their narratives then took place. Permission for amended life-stories to be digitally archived was obtained, as well as permission for the completed life-stories to be housed on a then inactive website (see notes for online access details). Participant approval for the content of the stored narrative was obtained at a third meeting.

In commencing the main study, information about organisations providing support to older people with intellectual disabilities in the Republic was obtained through the National Federation of Voluntary Bodies' website. Letters of introduction, including details about the study, were sent to the general managers of the organisations listed. This letter invited the staff of these organisations to liaise with people who used their services who met the criteria and who would like to become involved in the project. The criteria for inclusion in the study was that participants be over the age of 60 years and able and willing to take part in the project.¹ At the time of writing (January 2009) 11 people have shared their life-stories. Subsequently, 10 life-stories have been included on the website.

All the names of participants whose life-stories are housed on the website have been changed, as have the details of all other people and places mentioned in the life-stories. However, the experiences described are as the participants wanted to tell them to the researchers concerned. To further protect anonymity extracts included in this paper refer to life-story participants by age and gender only.

Findings

Establishing the 'deficiency' label

This part of the paper presents brief extracts from individual narratives gathered from those who have participated in the 'A Story to Tell' project to date. They outline how the acquisition of the label of intellectual disabilities (or its historic equivalent) was instrumental in the subsequent exclusion of participants from family and community life. Memories of how participants failed to measure up to external standards of competence and ability feature directly in some of the narratives. The following excerpts offer insight into how classificatory practices of medical science underpinned this process (Gillman et al. 1997):

... it was in a room of some hospital in Dublin...Well he gave me a series of tests, doing puzzles to see if I can put them together, to see what your IQ was. I got some of it right and some of it wrong ... I went outside and my mother and father went in. I didn't hear what went on. When we went home they told me that I was going to some school that could cater to my needs. That's how it all started... (male, 54)

... when I was fourteen I went up to the training centre for physically handicapped. I went up to C first and got the ambulance there and then went up to DL. It was a kind of hospital. The Doctors up there wanted to see what were wrong with the left side, me left leg and me left hand... (male, 59)

... when you went in first you had to go to this place. It was like a clinic for being assessed. You had to lie in bed for a couple of weeks. They had to mark your clothes. Then I went to one of the buildings ... (male, 54)

... They'd be watching, kind of like over you and telling you what to do. But at the same time they'd report back to the doctor on progress and getting on with. You had to wait for the doctor to come along. You sit down at the side of the bed. ... then the doctors come along and then they were talking. They wouldn't talk to you now but they'd be talking between each other and telling, you know, what will be happening to the patients. They didn't say nothing to me... (male, 59)

Other narratives reveal a less definite, yet still powerful link between perceived deficiencies, recalled as poor scholastic achievement, and subsequent placement in an institutional setting:

... I went to F ____ because I was mental handicap. I do nothing at the school. I didn't learn nothing. I dunno why. I didn't learn to read or write I didn't learn the books or nothing. Mental handicap I don't know... (female, 62)

... I was very slow. Disability means that I haven't got the full (pause) I haven't got the full (pause) there's some things that I don't understand. I wasn't very good in school. I wasn't very bright... (female, 64)

Participant's recollections revealed that practices of exclusion were legitimised through a process of measurement of (dis)ability, which intertwined within already situated religious and secular systems that relied heavily on confinement as a means of ensuring a socially compliant, homogenous and cognitively able society (Garrett 2000; Ryan 1999; Smith 2007). Participant's lives became caught within the interplay of biomedical and social practices of repression that characterised Irish society in the middle decades of the twentieth century. As other researchers have noted, these systems were particularly but not exclusively damaging to the subsequent life choices and chances of girls and women in the Republic (Culliton 1996; Raftery 2003). The following extracts illustrate the effects of labelling and confinement on the people in this study:

... He said take off your clothes. That was the sick ward. He said take off your clothes. I want you here for three nights only. He had the habit and beads around. I thought he was telling the honest truth. He told a lie. I'm still here. I'm forty years here ...(male, 79)

... I spent a lotta time down with the nuns. Partly all my life really with the nuns. Mum left me by the door or somewhere I don't know. She left me there anyway...(female, 64)

... All I know is I was 38 when I came, on the 6th April, 1974. Well it broke my heart, after 14 years working at home. I done all that work for 14 years, got their dinners ready and everything. And I used to make the beds after that. 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... (female, 69)

Testimonies of resistance and struggle

While the narratives suggest causal connections between people's perception of some sort of 'lack' or 'deficit' and their memories of social disengagement and dislocation, the stories also document how participants consciously resisted the effects of exclusion and confinement to which they were subjected (Gillman et al. 1997). One response to the reality of institutional life was, at least for some people, to seek a means of escape from it – as the following excerpts illustrate:

... I used to go to bed at night (then I'd) climb out the window and run away. I use to hide behind pillars to see if there was anything looking at me. Then I'd go out through the front gates ... (male, 54)

... I wanted to go. I ran away three times...(male, 61)

... I used to run down the main street kind (?) and to go on down to the village that was just adjacent to L _____. I used to run for hours and hours. I often didn't get away with it and I was picked up by the guards... (male, 54)

... I had a pass key you see. I'd open the door. He didn't know where he was going, he was from Wexford, and he's going straight down the drive. (The priest) was very cross. Have you keys? I said no, I haven't Father, I said. I'd pretend I hadn't. But I had one ...(male, 79)

Other extracts detail the day-to-day struggles experienced by participants in the face of what could be extremely difficult living environments. These include examples of the kinds of punishment meted out in response to real or perceived acts of defiance:

... I moved to a community house. I lived there with three others, two boys and one girl. I stayed there for three months. It didn't work ... I couldn't control what was happening to me. It was like a monster inside me and I couldn't control it. I used to pray to God I wouldn't lose my temper. I could feel it in my head. I lashed out at staff and others. I'd hit them, slam doors, I'd give out a lot, cursing and talking to myself. I was moved to different houses because I was always complaining and not getting on with people I lived with. I kept looking to find some place I could be happy... (female, 45)

... My hair was chopped off like a boy.... Oh I didn't like it, but what could you do? It's life, you know, and when you got a beating, a good slap and stuff like that you couldn't tell anybody. They'd give you a good slap because you'd be wild and being bold and being cheeky. I was only a child at the time... (female, 64)

... She was a very cruel nun. She locked me in a cupboard and then she locked me in the morgue. The head nun, Sister ___ was going to kick her out because of that... (female, 51)

Unsurprisingly, narratives also revealed many heartbreaking instances of individual compliance with institutional regimes. The following excerpts represent participants' responses to the harsh and sometimes punitive actions of certain staff members:

... They'd be a lot of fights... arguing between their-selves, giving out. So they'd put you to bed ... and maybe there for a few days. Stay there, and you'd be left out. You'd want to behave yourself. You wouldn't be blaggarding you wouldn't. It worked all right it did. Kind of taught a lesson on it ... (male, 59)

... They used to punish me on the floor kneeling down on my knees from two to three. When three came they would tell us to get up and behave ourselves and if we didn't we'd go back down to that kneeling down business again. So we were good ... (female, 64)

... I never complained No, no. I never get into them habits of complaining ...
(male, 63)

These actions were not confined to staff members alone. The following participant's account details the difficulties he experienced at the hands of other residents:

... Sometimes they'd bully you for money. Sometimes they'd verbally bully you and some of them would set out to physically harm you. It wasn't in the dormitory itself. They wouldn't go carry on like that in the dormitory (but) where nobody was looking. It could be in behind a shed in the schoolyard. They tried to drown me on three occasions by holding my head under water. I was powerless to resist. I remember one time three big fellas blindfolded me and tied me hands behind me back and led me somewhere up about thirty feet off the ground in an obelisk and lent me over it to throw me off. They said if you don't get me money we're going to throw you off. They kept holding me down until someone was passing then they let go and ran away. I tried to get the cord off...
(male, 54)

The same account also recalls this participant's experience with a member of the wider community:

... At first he got friendly with me, you know what I mean. Eventually he used to offer to buy me cigarettes or sweets and stuff like that. He enticed me into a room. That's when it started. He did it to me. It happened on about four occasions, twice in a runners hut. He picked me up in the street one night and drove me to a bed and breakfast. Did it there again. I think the last time he was trying to get me to stay the night with him ... (male, 54)

Memories of kindness

As well as detailing the socially and emotionally damaging aspects of participants' experiences in institutional settings, the narratives also highlighted how the kindness of significant others contributed to a sense of somehow also being connected to a caring community. In the extracts below, memories of difficult experiences are counterbalanced by recollections of positive interactions with relatives, workers, friends and wider community members. Recalling these interactions continues to be a source of warmth and comfort to the participants concerned:

I was at home watching television at the time when the whole thing (sexual abuse) came out. It suddenly hit me. I worked in the day-care centre in ___ and I told the manager there, who believed me. She got me to see somebody else that gave me the information about where to go ... (male, 54)

... One brother is very fond of me. He didn't know I was here in the hospital. I rang him. He never knew I was involved in hospitals. He said 'where are you now, I was going up to your house' I said 'I'm in S __'. 'What are you doing there?' he says. I said it's a long story. So I brought him in here. He got an awful shock ... (female, 62)

...A* came up to Galway. He's from Sligo now ... I said to him I'm never to go home, I'd love to go home. Pray for me that way I'd go, I said. A* looked into it for going home and coming this way. I was very happy. I like to be here 'cause I like to be near home. I liked coming back to my own part of the country ... (male, 63)

... I worked with a lady called B* ... she used to bring me to bingo on a Friday night. She used to bring me up and down in the car, her own car with her husband. She died- Lord have mercy on her - with a brain tumour. She had to retire, and she didn't live long to enjoy her retirement, then she died ... (female, 69)

... C* was there and she was very good. She'd take me for cooking and stuff like that and she took me for my assessment. She said go in the fridge and see what shouldn't be there and what should be there... (female, 64)

... he was a staff. He used to be down here. A*, did'ja ever hear of him? He was here workin' in the hospital here. I was sitting down on a chair and he said, jokin', a woman and a man kissing one another on the television. I started laughing aloud. A*_d do that and I'd burst out laughin' And then Father M_'d say, stop A*, don't be putting G laughing, see. Scottish this priest was. Stop A*, don't be putting G laughin'. And he used to say that and he'd be jokin',... kissing and kissing one another on the television. I'd laugh ... (male, 79)

A number of the narratives illustrate how older people can reach a deep level of acceptance of what had happened to them. Finding a wider perspective has enabled these individuals to take up a more reflective position in relation to the emotional distresses of the past:

... 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 had a family which is more than a lot of people had. I had a lovely home so I didn't really need to be doing that at the time. That's what I learned from it. Running away from it didn't do me any good anyway because by the time you're finished running away you still had to face it when you come back. So it was really pointless in that respect.... (male, 54)

... So in 2009 I'll be sixty. I'll be in my sixties. I'm getting on. Give me another five years and I'll be out in the retirement home. I'll be doing nothing but sitting down all day, having a rest. Or going for a spin and that'll be all right. Up in the garden now where I worked, there's a lot of young people there, and they like messing and blaggarding. They're at that age you know. They didn't mature. 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...(male, 59)

... I'm not wealthy but I'm comfortable as the man says. People here look after me. I think myself that if you are happy everyone is happy. If you are sad everyone is sad. And you have to grin and bear it. I am happy. I am as happy as the day goes long. And I'm as happy as Larry ... (male, 61)

... So that's where I'm at. I know I have my ups and downs, me bad days and me good days and all that, but sure we all have them. They have brought me on like, even the staff and the nurses and the matrons and all that ... (female, 64)

... I love this place. It's better. Well I can go home every weekend and I'm near my sister. I have two nieces and one nephew. And they were good to me when I were in hospital. They came up to see me and some ... (male, 63)

However, despite these more reflective accounts, regrets about unfulfilled lives and lost potential also feature, as exemplified in the following extract:

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 having a couple of kids and grandkids by now. I never ever got that chance. I didn't give it thought often until now ... (female, 64).

Those held in state and voluntary institutions in Ireland who were the victims of sexual abuse have been offered official redress for the ordeals they experienced. Yet others who experienced 'the absence of due process, exploitative and dangerous work practices, the denial of educational and human development resources' (Smith 2007, p. 63), along with the emotional trauma of institutional practices, have yet to receive any official acknowledgement of how coercive practices impacted on the course of their lives. This acknowledgement, as well as concerted efforts to redress the injustices of the past in relation to older people with intellectual disabilities by service providers and policy makers alike, is long overdue.

Discussion: the value of life-story work

Disseminating the life-stories of older people with intellectual disabilities in Ireland through access to the website will provide a solid measure of achievement in respect of Ireland's obligations to Article 8 of the UN Convention on the Rights of People with Disabilities – to foster awareness and respect for the rights, capabilities and contributions of persons with disabilities. However, this project also demonstrates the potential value of a narrative approach to the more effective operation of the intellectual disabilities service sector in the Republic. Commentators suggest that the lack or loss of background information relating to those who have been in long-term, institutional care is an issue that continues to compromise the lives of older people with intellectual disabilities (Gillman et al.1997). Without accurate details about their past, it remains questionable how effective long-term future changes envisaged for all people with intellectual disabilities are likely to be for members of this group. Life-stories collected for this project reveal how often legitimate requests for supports and services made by older people are downplayed, if not outright ignored, by those who work in the service, advocacy and policy sector. These narratives reveal the importance of attending closely to what older people have to say about the past and present conditions of their lives.

Developing a life-story approach to service planning and provision would allow the insights these narratives afford to significantly enhance an organisation's ability to question its taken-for-granted practices. As these extracts and the life-stories housed on the website reveal, life-stories have the capacity to provide feedback to staff, managers and researchers working in the intellectual disabilities field. However, undertaking narrative work means having to learn specific skills in listening and relating. Gibson (2006) outlines the following approaches necessary to use when undertaking any kind of life-history/life-story collecting work. These include:

1. Active listening, by noting what is said and what isn't said

2. Emphasising, by being able to share another's world without losing your own
3. Attending, by being available for people
4. Being nonjudgemental, by accepting people as they are
5. Not being frightened by expressions of painful emotions
6. Being able to enjoy stories and be interested in the past
7. Being disciplined, but being able to share your own thoughts if asked
8. Being able to reflect on and critically evaluate your own work
9. Being able to accept feedback and offer feedback to others.

This list represents a set of very useful skills that could also be transferred to support practices in general.

Conclusion

More work is needed on how to address the difficult moments that feature particularly in the life-stories of those who have been subject to harsh institutional practices (Ellem et al. 2008). Because life-story work can mean listening to accounts of very traumatic memories, the collecting of such narratives may be stressful for all concerned (Atkinson 2005). This means that while definitions of what is 'sensitive' depends on context and cultural norms and values, those who collect life-stories – as well as those who recount them – will need opportunities to reflect on and make sense of these accounts. Care is needed, therefore, to build in support for all involved in life-story work. With this proviso, it is our contention that the use of life-stories in service planning and delivery can enhance the quality of support for people with intellectual disabilities.

Footnotes

1 Older people with an intellectual disability who were not 60 years or over, but who were keen to participate, were also invited to work with the project and to submit their life-story for inclusion on the website.

Notes

The Royal Albert Hospital Project archive can be accessed at <http://www.unlockthepast.org.uk> [Accessed 25 October 2009].

The Open University Social History of Learning Disability Research Group can be accessed at <http://www.open.ac.uk/hsc/lds/site> [Accessed 25 October 2009].

The Online Museum of Disability can be accessed at <http://www.museumofdisability.org> [Accessed 25 October 2009].

The A Story to Tell Project can be accessed at <http://www.tcd.ie/niid/life-stories> [Accessed 25 October 2009].

*[Corrections added on 10 July 2010 after online publication 17 November 2009: Real names have been made anonymous to A, B, C. Acknowledgements extended to include Marie Curie 6th European Community Framework Programme.]

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