



Commentary

Exploring My Life Path by Asking 600 People What They Love about Theirs

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Abstract: A young man with Down syndrome and an early adopter of self-managed supports wanted to have a great life, but he needed to be sure what a great life was for him. He decided to ask successful people, “What do you love about your life?”, which he felt was a question that gets right to the heart of the matter. In this paper the young man and his father will outline their journey as co-researchers in collecting/filming 600 stories across ten countries, with some interviews prearranged but many occurring spontaneously at music, film, and arts festivals. The initial findings of “what people loved about their lives” fall into the following categories: Family, Work, Home, Travel, Health, Pets, and Life Itself. Positive side effects for the young man covered: self-confidence, ability to connect with people, opportunities, working relationships, and ongoing friendship. The implications of taking a social journalism approach to collecting stories will be discussed in line with the question “What makes for good inclusive research”? The journey of the co-researchers speaks to the outcome that it is worthwhile to research your life path, accessing elders’ wisdom. The tools of inclusive research are powerful when applied to a citizen’s life questions. Each person values their life in unique ways, yet there are many commonalities.

Keywords: down syndrome; qualitative research; quality of life; self-advocacy; happiness



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Introduction

Fionn is a young man with Down syndrome who rents an apartment in Galway. Jonathan, his father, supports him to live independently. Together they follow Fionn’s dreams: they travel to experience unique landscapes and natural phenomena; and they meet communities and individuals, by offering workshops and talks, and by performing music. They weave all these together into amazing adventures.

Fionn is one of the first in Ireland to adopt self-managed supports. He wants to have a great life, but he needs to be sure what a great life is for him. Gathering information about what is a great life for others was a way to gain clarity on his question: to determine his life path. And through the process of meeting, greeting and interviewing many people, a great life is happening along the way.

There has been much written about the value of inclusive research in line with its principles of ensuring that the research questions are relevant to the life of the person involved in collecting information (Johnson and Walmsley 2003). Their reflection will demonstrate how such data collection has been life-giving for Fionn, leading him to widen his circle of contacts as well as provide him with “an adaptable way to a sustainable and meaningful career” (Angus 2022, p. 1).

How They Went about This Reflection

As a team of two co-researchers they discussed what they would like to share about their inclusive research journey and how it had impacted Fionn’s life journey. They had several discussion sessions following which Jonathan would draft the ideas into a script that Fionn would listen to and then agree or suggest additions and/or modifications. The

reflection is a joint effort using Jonathan's strength as a writer and Fionn's strength of contributing to discussion and interpreting ideas from his own perspective of being an inclusive researcher. The reflection is written in the third person which allowed for some details being personalised to either Jonathan or Fionn versus the plural use of "we". For the purpose of the reflection there are a number of what the authors have described as Spin Offs for Fionn arising from doing inclusive research.

The Happiness Project

In this commentary the authors have chosen to reflect on what they have learned from their Happiness Project which they have developed and which is an ongoing citizen research project containing more than 600 open-ended interviews filmed in ten countries over seven years. Initially they met only with people with Down syndrome. This project began in the summer of 2013, when Fionn was a teenager. It arose from the desire to share insight into the lives of a small group of people with Down syndrome from the west of Ireland. It was decided to make a video to be shown on the first night of 600 km charitable cycling tour for the benefit of people with Down syndrome. Jonathan asked Fionn to decide on a single interview question they could ask all of the participants in the film, and Fionn suggested: What do you love about your life?

For Jonathan, the question initially sounded a bit awkward, a bit too naked or naïve. The more he ruminated with it, the more the simple brilliance shone, a profound question that could be asked a dozen times of the same person and could elicit a dozen responses, one that could lead toward greater appreciation of one another's lives. It illustrated well the core principle of inclusive research that research question/s need to be owned by the person with the lived experience of disability (Johnson and Walmsley 2003).

For the Happiness project it was important to film a variety of people with Down syndrome, including those who, through communication challenges, could not be expected to speak on camera. The method settled upon for this latter group was to query a loved one, usually a family member, and film the person doing the activity they love. This way the project was far less language dependent. All interviewees both verbal and non-verbal were videoed doing things they love: ocean swimming, surfing, racing greyhounds, baking cakes, dancing, playing with pets, and driving a car.

An edit of the video was made (with Fionn playing fiddle for the soundtrack) and it was warmly received when screened at the end of the first day of the race for the tired cycle riders. A subsequent article in the local paper caught the eye of a national TV chat show, and they were invited to show clips and talk about it as guests on the show.

For the purpose of the commentary there are a number of what the authors have described as Lessons Learned for Fionn arising from working on inclusive research projects. These are now explored below.

Lesson Learned: Doing the Pilot Happiness Inclusive Research Project Enabled Fionn to Speak to the Media as an Agent of Attitude Change for People with Disability

The end of the cycle race could have been the end of Fionn's search to understand what people loved about their lives however Jonathan was still grappling with how to help him settle on something fulfilling, where his gifts could be shared. They both agreed that it would be foolish to rush into a career decision and determined to continue the Happiness Project, extending their focus to include people with a range of different interests and accomplishments. By broadening the group and learning what was most important to a larger group of individuals, Fionn believed that he might gain insight into areas of life that he had not thought about in relation to his own life. At the same time both agreed that the project was a way of developing their father /son relationship as one built on shared experience of doing research together.

Recruiting People to Answer Fionn's Question

Fionn's network of contacts reflected how, with Jonathan's support, he had built a start-up career that included his interests in music, art, and education. His wide network came from his busking on the Galway traditional music scene playing the fiddle, from exhibiting his artwork both in Ireland and beyond and doing inclusive research as a member of the Inclusive Research Network of Ireland (http://www.fedvol.ie/Inclusive_Research_Network_IRN/Default.241.html, Available Online: 26 November 2022) and Citizen Network (<https://citizen-network.org/map/fionnathan-productions>, Available Online: 26 November 2022). The fluidity of Fionn's world led him to decide on approaching people for interviews on meeting them at the range of events he and Jonathan attended together. This covered concerts to gallery exhibitions, from lectures to movie premiers. Such an approach was not unlike street interviews done by journalists (Gubrium and Holstein 2001). This decision coincided with Fionn and Jonathan gaining free access to these types of events as journalists.

Lesson Learned: Doing Inclusive Research Led to Fionn to Be Recognised in Other Valued Roles Both as Interviewer and Event Journalist

As part of the flexible approach to recruitment potential participants were asked for their verbal consent to film them answering the single question put to them by Fionn., What do you love about your life? It was explained by Fionn supported by Jonathan how these videos were recorded to learn about the person's life, so Fionn could gain insight into how other people lived and how this might help him to decide what he wanted to do with his life. They shared with each interviewee how they would post the interview online, providing them with the link and contact details if they wished to have the video deleted. As their interviewing continued their video making skills also grew. They became adept in using professional film making equipment, including digital cameras, tripods, microphones, and lights. They found that a smartphone often worked best, as people were more at ease and appeared to speak more freely. They agreed with Wolfensberger (2013) that their new roles of interviewer and journalist added value to their lives.

Lesson Learned: Doing Inclusive Research for Fionn Gave Him Experience in Learning New Skills on the Job

- *Doing the Interviews*

The interviews were posted on Fionn's YouTube channel, titled Fionnathan Presents The Happiness Project: What Do You Love? (<https://www.youtube.com/channel/UCEUj8gOAbuMUXdZRE5Yw0PQ>, Available Online: 26 November 2022). Here the date of the interview, location, a description of the events surrounding events, a biographical sketch and links to the interviewee's online profile are available. They were then cross promoted on social media such as Facebook and Twitter. Some of the videos were linked through to Fionn's website, www.fionnathan.com, Available Online: 26 November 2022. Interviews about the project were done with traditional media (TV, radio, and newspapers) as well as podcasts and blogs.

The methods used by Fionn, with Jonathan's support, to hear and record what people loved about their life, supports the issue raised by (Milner and Frawley 2019) who have called for action in inclusive research to provide space for researchers with the lived experience of disability to select how they collect data without being reined in by traditional research methods. For data collection to work for Fionn and Jonathan as two co-researchers, one with an intellectual disability and the other as a supporter, the data collection needed to fit with the spontaneity of the event where they meet potential interviewees. Also, they did it together challenging the traditional belief of a potential conflict of interest between them as father and son. Their view in response to such potential criticism was that doing research together reflected their respective roles as partners in a company that they had set up called, Fionnathan Productions as a social enterprise that aims:

1. to help Fionn have a great life
2. to share the journey in hopes of helping others to have great lives
3. to change the world by removing obstacles that prevent people from having great lives (Angus 2022, p. 19).

Making media productions, doing research, and promoting inclusion provided them with an opportunity that moved beyond vested interests to developing sustainable interests that became life enhancing for Fionn.

Looking back to the beginning of the pilot, there was a moment when the Happiness Project might have never started. "On the first day", Jonathan reminisced, "as we travelled out to collect stories, Fionn spoke from the passenger seat, saying, 'I think maybe you should ask the question, and I'll hold the camera,' to which I responded, 'How about you try it out. And more than a few, so you know what it's like past the start'". Fionn agreed, leading to Jonathan's viewpoint that he has grown to exude self-confidence. He is surprisingly capable, and his good cheer is disarming, cutting through social barriers and calling up honest reflection. People feel safe opening up to Fionn, it seems, intuitively recognising a lack of guile. Perhaps surprisingly, as meeting people with Down syndrome is a relatively rare occurrence for many in society, those we interview seem to find Fionn immediately relatable. Simply put, he's a highly skilled interviewer.

Lesson Learned: Doing Inclusive Research for Fionn in a Space That Is Not Bounded by Traditional Methods Allowed Him to Collect Information in a Doable Way That Built His Confidence as an Interviewer

- *What Was Learned about What People Loved about Their Lives?*

The interview collection now numbers over 600 stories. More than 100 participants are famous enough to have Wikipedia pages about them. Interviewees' ages cross the adult lifespan, from teenagers to people in their 10th decade. Many of the people they have collaborated with have intellectual or physical disabilities with important things to say.

The technique that was used in the pilot project to interview subjects with all levels of speaking ability served to support them in engaging with a very diverse body of participants. They shared thoughts with a deaf interviewee through a translator who spoke and signed. With non-English speakers, they used a combination of gestures, smiles, and smartphone apps.

This fluidity of approach allowed the interview style to change to fit the circumstance. Interviews with the touring troupe from Shakespeare's Globe Theatre presupposed their love of acting. Fionn instead asked a rhyming couplet: "Which line, from this play, is your favourite to say?"

Many people find being asked by Fionn, "What do you love about your life?" quite a moving experience. Dozens say, "that's a wonderful question," or sometimes "what a beautiful question," or even "you probably have asked me the most important question you could ask anybody." Sometimes people say "um umm," or "that's a really difficult question," and two even said "that's an awful question." Generally, though, even such respondents warm to the theme.

Once, a touring musician from America settling in for the interview asked about the origin of Fionn's name. Briefly the Irish myth of the third-born son, a simple man who gained all wisdom from the Salmon of Knowledge unintentionally, while serving others was shared. In the ensuing interview, the participant referred to this story to describe her creative process, saying, "You can't be like a king. One has to be like a servant, one needs to be 'broken enough'".

Each person interviewed valued their life in unique ways, yet there are many commonalities covering the following eight areas: Family & Friends; Work; Travel; Home; Nature; Health and Well Being; Hobbies and Education.

Here are some direct quotes selected by Fionn that relate to these categories as ones that he found that were meaningful to him. He pointed out that all the quotes come from a place where people were living lives doing things that made them happy. What both Fionn

and Jonathan found amazing was that there were no negative answers. They wondered if their own excitement to ask this question led people to only think positively. The power of positive thinking was at work.

Family & Friends

“The influence of my mother.”

“My family, my friends, my grandchildren.”

“I love my family. Because of them I able to keep grounded, and I remember that what I do, I’m doing for them”

Work

“I try to love almost everything, approaching our lives and our work like we’re making art and music.”

“I love making films. I get to do a job that I would pay to do—please don’t tell Disney that.”

“I am enjoying a number of opportunities to grow in my profession. I have been assisted by conservation colleagues not only in Zambia but in the Southern region.”

Travel

“I enjoy traveling to strange and new places.”

“I love traveling. I think that has really changed my life.”

“I love being here in Dublin for my first time.”

Home

“Home.” (“And what do you love about home?”) “Breakfast.”

“I love going place, which only makes coming back home all the sweeter.”

“I love living here on campus and having fun with all my frineds.”

Nature

“I love nature.”

“I really enjoy getting close to really wild animals, and big wild animals, at times. And then I like getting a chance to watch them for a long time.”

Health and Well Being

“Gathering primary sources, and helping people use them.”

“Interdependence, and being there for each other, is way more valuable than independence.”

“I love that my live is surprising in the best and deepest ways.”

Hobbies

“I love the fact that I discovered, by sheer chance, that I could play music.”

“What I love about my life is I’m a teenager, and I listen to music.”

“I love gardening.”

Education

“Opportunities to never stop learning.”

“Men like you, asking questions like that.”

“My son taught me that pretty much everything the world values is of no value. That money isolates you from other people.”

Responding to the question “What do you love about your life?” often leads to emotional responses where tears and laughter are shared, and Fionn has received many spontaneous hugs. Here is a favourite moment, when Fionn’s interviewed a retired secondary school history teacher in a small village.

“That’s a profound question, and it would take me a long time to do it justice. But I would say . . . I will just tell you that I have been blessed, in my studies, in my job, in my entire life, with good health, a good wife, a happy family, and what can I say? a great, great life, in every possible situation.

And I am thoroughly happy. I have so many blessings, and so many things to be grateful to.

And thank you for asking me a question that’s so profound, so deep, and profound, and would take, actually, a long time to answer adequately. But it is a hugely important question.

Now, could I ask you a question?”

“Sure.”

“The same question to you: What is most important to your life?”

“I suppose, this moment, interviewing you”

(Nearly overcome with emotion) “Bless you”.

Lesson Learned: Doing Inclusive Research Led to Fionn Being in Receipt of Positive Statements about His Role as Interviewer, Leading to him Feeling That He Was Appreciated

- *What Was Learned by Fionn about His Life?*

Fionn and Jonathan agreed that the most enjoyable part of the research cycle was sharing what they had learned with others who are interested in the topic and receiving their responses. They have been asked to deliver talks to social science students on courses in thirty colleges and at multiple conferences, in cities such as Honolulu, Copenhagen, Amsterdam, Glasgow, Bristol, Sydney, Brisbane, Vancouver, Montreal, Detroit, Philadelphia, and Austin. On the surface their presentations may appear as purely educational, but they serve a deeper purpose for Fionn being recognised as a valued presenter arising from doing research in a manner that best suits his abilities and interests. This outcome was life enhancing for Fionn as it paved his life pathway with speaking opportunities that would often snowball into other invitations. For example, families would often refer Fionn to other family groups after gaining insight into his life as inspiration for their own family member with a disability. A further example of one presentation leading to another happened three years ago, when Fionn had an opportunity to interview Tim Shriver, Chairman of Special Olympics. He was profoundly impressed by the question, and during a dinner celebrating the launch of a UNESCO Chair, asked Fionn if he would partner to deliver the post dinner address. Fionn described his project to the gathering, and Tim invited all to reflect on what it was they loved about their lives, providing a minute of silence. Then, volunteers shared their responses to the question with Jonathan recording it all—six more interviews, in the bag.

What was also learned by Fionn was that celebrities, leaders, and other people of influence was open to being interviewed if the question is appealing and the approach flexible, and ideally instant. In getting to ask this one major question about what people love about their lives the outcome for Fionn has not been a chosen pathway emulating anyone person that he has interviewed but rather he has become more himself becoming not only an expert on what people love about their lives but also being open to becoming an Ambassador for a Global for Citizen Network (<https://citizen-network.org/about/citizen-network-research>, Available Online: 26 November 2022), as well as founding officer of the National Down Syndrome Policy Group (NDSPG) UK (<https://ndspg.org/who-we-are> Available Online: 26 November 2022). Recently, he lobbied 107 MPs (probably a world

record for an Irishman) contributing to the recent passage of the [Down Syndrome Act \(2022\)](#). As a Research Officer for the NDSPG, he with support from Jonathan established an Advisory Group of people with Down syndrome from all around England. You can probably guess what the first focus group question was.

Perhaps the biggest honour of all: Fionn is Chair of the new Special Interest Inclusive Research Group for the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) (<https://iassidd.org/sirgs/inclusive-research/>, Available Online: 26 November 2022) and the first Council Member with intellectual disability in the organisation's 58-year history.

Lesson Learned: Asking People What They Love about Their Lives Has Enabled Fionn to Recognise That He Has Leadership Potential Becoming a Member of Both Inclusive Research and Advocacy Groups Which All Play a Part in Building Him a Sustainable Future

Conclusions

Fionn and Jonathan have approached this reflective commentary as two co-researchers describing a body of work that has warmed hearts of 3 million others (latest YouTube count <https://www.youtube.com/channel/UCEUi8gOAbuMUXdZRE5Yw0PQ/about>, Available Online: 26 November 2022). They hope that this journey, attempting to discover a young man's life path, might stimulate interest in both professional academics and aficionados of knowledge to break (or at least bend) some of the rules and conventions of who can do research, and for what purposes.

Finally, it will come as no surprise that when Fionn was last asked about what he loved about this life his answer was "I love meeting people from all corners of society, and I love to hear their stories and share my stories with them. I want to make the world a place where everyone belongs, and I think that can happen when we listen to each other."

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