Autistic Voices on Film

Autism and Neurodiversity
Exploring Diagnosis

Evaluation report produced by:
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Contents

Introduction

Exploring Diagnosis is a research project based in the Egenis Centre at the University of Exeter “exploring the role that diagnosis plays in society and in medicine, using diagnosis of autism spectrum disorder (ASD) as a case study. On the way, they aim to celebrate and value the abilities and attributes of the neurodiverse community.

Diagnosis can be viewed as:
- A way to categorise people
- A social process which involves many people and takes time
- An intervention in itself, with consequences for health, both positive and sometimes negative

With more and more people being diagnosed with an autism spectrum disorder (ASD), it is important to ask why, if, and how, diagnosis is of benefit. The ExDx research group carries out their research through listening to the views and experiences of adults who have a diagnosis of ASD. They also work with clinicians, hearing about how they make decisions when diagnosing autism via partner organisations.[1]

While a diagnosis can release funding and other forms of support, it can also lead to stigma and judgement. A diagnosis also assumes a medical / science frame which can be hard to challenge.

Ginny Russell holds a Wellcome Investigator Award (grant reference number: 108676/Z/15/Z). Wellcome place a strategic priority on public engagement with research (PER) and as such provide a ring-fenced fund for researchers holding a grant from them to undertake PER: the Research Enrichment - Public Engagement fund. Ginny was successful in applying to this fund to undertake the work this document reports on.

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[1] https://blogs.exeter.ac.uk/exploringdiagnosis/

The project: Exploring Diagnosis: Autistic Voices on Film

The PER funding enabled the production of three short films to challenge current narratives about autism and the diagnosis of autism. Target audiences for the films include:

- Clinicians
- Educators
- Researchers
- Autistic adults
- Parents of autistic children

The intended outcomes for the project include:

- Production team have a greater awareness of the culture of diagnosis, identity and neurodiversity
- That viewers of the films have a greater awareness of the culture of diagnosis, identity and neurodiversity

A logic model of the project is available here:
http://blogs.exeter.ac.uk/exploringdiagnosis/files/2018/09/Logic-Model-Films-Version-3.pdf

The films were co-produced between the research team, Calling the Shots film production company and people with a diagnosis of autism. People with autism provided audio descriptions of their experiences. Neurodiverse artists and artists with autism created the visual material for the films. A cellist was commissioned to create and perform the accompanying music for the films once the visuals were created.

Project team

Ginny Russell (Principle Investigator)
Jean Harrington (Project coordinator)
Jeremy Routledge and Dominic Pitt (Calling the Shots)
Debra Muzikar (Art of Autism)
JA Tan (artist)
Angela Weddle (artist)
Eddie Callis (artist)
James Frye (artist)
Sarah Moody (musician)
Helen Featherstone (evaluator)
The seven people who were interviewed for their voice recordings to be used in the films were promised anonymity so their names have not been included here.

Project timeline

Table 1: the timeline of the ExDx public engagement project

Date	**Activity**
Oct 2017	Funding received
Oct 2017	Calling the Shots appointed External evaluator appointed
Mar 2018	Project Coordinator appointed
Jan-Feb 2018	Animation workshops
Nov-Dec 2017	Voice-over recordings made
Mar 2018	Artists commissioned
Oct 2018	Cellist commissioned
Apr 2019	Films finished (Launch)
April 2019	**Egenis, Byrne House**
April 2019	Trailers shown at SAP Gala in London
May 2019	Academic away-day – films shown with discussion
June 2019	**Mainly Mozart, San Diego**
July 2019	**Spike Island, Bristol**
August 2019	Brocher Foundation (institution which supports month-long residencies for twelve academics) – films shown with discussion
September 2019	All Wales Neurodevelopmental CEN, Cardiff
November 2019	Researching Disability and Impairment: creativity, engagement and social change, Royal Albert Memorial Museum, Exeter (part of the Festival of Social Sciences)
November 2019	**Cornwall Film Festival, Falmouth**
December 2019	Films available to watch - STEAMM, Exeter College

Evaluation

Approach

Undertaking evaluation is a requirement of projects funded through Wellcome's RE-PE scheme. Helen Featherstone was appointed as an independent evaluator early in the project's timeline and has been kept abreast of how the project is progressing through regular interactions with the project coordinator (Jean Harrington). This has allowed Helen to be aware of how the project is progressing, and to be a "critical friend" to the project. She has contributed a little to the decision-making process where necessary, particularly if decisions were likely to move the work away from the projects' aims and public-facing remit.

The project team had not previously developed films together, however, Ginny has a background in film making (before becoming an academic researcher) and the film company Calling the Shots have a strong history of working with groups who are traditionally under-represented and under-served through culturally dominant creative practices. In their words they are "all about widening participation and helping people express themselves through creative media."[2].

The ExDx Team had previously worked with US-based Art for Autism and they continued to work with this partner for the production of the films for this project. Art for Autism administered a call for artists and the associated administration related to the commissioning and payment of the artists.

Sarah Moody was appointed to compose and perform the accompanying music for the films. The team explored the possibility of commissioning an artist with ASD but the need for creating music to a tight brief and deadline meant the team felt that Sarah would be more appropriate. Sarah's expertise as both composer and performer and her experience of working on similar projects meant the team commissioned Sarah to compose and perform the music.

This report will provide both a description of the work done (to act as a record for the team, the funder and the project team) and how well the project's aims were met. In line with the participatory nature of the work, this report has been developed as a partnership between Helen and the project team, in particular with Jean Harrington.

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[2] http://callingtheshots.co.uk/about/

Research Questions and Tools

This evaluation report will explore the following research questions (RQ)

> RQ1 Do the films help viewers to develop a more varied perspective on the effects of having a diagnosis of autism? Why?
>
> RQ2 What was it about the process of developing the films that resulted in this?
> RQ3 Did the project run smoothly and what can we learn from it?

The information presented here is taken from multiple data sources. These sources have been selected to reflect the various people (and groups of people) involved with the films:

- Observation and participation by HF and JH
- Questionnaire feedback from viewers (see Appendix for the questionnaire)
- Interview feedback from one of the voice contributors after seeing the films
- Written feedback from one of the voice contributors after seeing the films
- Interview feedback from the voice contributors at the time of being interviewed
- Focus group feedback from a group of people with autism who participated in the animation workshops and attended the screening
- Reflective feedback from the project team

The format for recording the data from the people with autism (written, interview or focus group) was determined by their preferences.

This is summarised in table 2:

Table 2 - summary of research methods

Who	**Why**	**When**	**How**
Interviewees	RQ2 and 3	At time of interview After screening	JH - interview HF - interview
Artists	RQ2 and 3	After screening	HF - interview
Project team	RQ2 and 3	Throughout the project	HF and JH
Audience members	RQ1	At registration (where appropriate) At event	JH - Registration HF and JH - participant observation HF -

			questionnaires HF - social media analysis @ExDx_UoE

It was originally intended that HF would attend the events, however this was not possible due to budget constraints (eg going to San Diego) or availability (eg Spike Island and Cornwall Film Festival). Where possible HF sent a substitute evaluator or relied on JH’s observations.

Due to the practical resource constraints associated with this work it was not possible to include every individual’s perspective on the project. However, we have collected data from people who are representative of the different groups of people who contributed to the work.

Results

The results presented here draw on the multiple data sources outlined above. For this evaluation we are focusing on four events that focused solely on the films and which had an explicit public remit. The four screening events all featured a panel discussion with some of those involved in making the films. The films have also been shown at several events aimed at academics, events that discussed research methods[3], and a showcase about arts and technology[4]. Evaluation wasn't conducted at these events because of the lack of specific focus on ASD and diagnosis.

The evaluation data presented here relates to the film screenings and panel discussions at:

- Egenis, Byrne House, University of Exeter (launch event) (30 people attending, no questionnaires, participant observation only)
- Spike Island, Bristol (18 people attending, 7 questionnaires returned)
- Mainly Mozart, San Diego (80 people, 15 questionnaires returned)
- Cornwall Film Festival, Falmouth (20 people, 13 questionnaires returned)

These events together reached 148 number of people. However, it worth noting that considerably more people have been exposed to the films. In some cases these have been passively (eg the SAP Gala where the films were on a screen on rotation, in others they have more deliberate eg Brocher Foundation). Literature was available for people to take away and many leaflets were taken suggesting an interest in the films.

The films[5] have been viewed 2754[6] times on YouTube with nine positive comments from people with autistic spectrum disorder. It is not possible to know more about who has viewed the films or what they have taken from the films.
The films were shared via a pinned Tweet on Twitter[7] which has had 20 retweets and 15 likes. This has been retweeted by academics, those involved with the project, creatives with an interest in autism, and people with a general interest in autism and neurodiversity.

The 35 questionnaire responses from the Exeter, San Diego, Spike Island and Falmouth events indicate that audiences comprised:

- People with autism (n=2)
- People with a diagnosis of autism (n=4)
- People who live with a person with autism (and in some cases friends and occasionally more distant family) (n=13)
- People who live with a person with a diagnosis of autism (n=5)
- People with a professional interest in autism (eg speech therapist, diagnostic services) (n=12)

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[3] Event titled: *'Researching Disability and Impairment: Creativity, Engagement and Social Change'*.
[4] https://www.eventbrite.co.uk/e/the-exist-steamm-show-tickets-78982652239#
[5] https://blogs.exeter.ac.uk/exploringdiagnosis/exdx-films/
[6] 3 January 2020
[7] https://twitter.com/ExDx_UoE/status/1151461347135283201

- *People with an interest in the arts (in particular social film-makers) (n=2)*
- *People are generally interested in society (ie no direct connection to autism, art or diagnosis) (n=1)*

There are more than 35 responses detailed above because people could tick as many boxes as applied to their situation.

This is a more diverse audience than initially intended, those in *italics* were not listed in the initial proposal. It is not clear that the films, so far, have reached formal educators as was intended.

Secondary and tertiary educators were exposed to the films through several events: academic away day, Brocher Foundation, All Wales Neurodevelopmental CEN, Cardiff, STEAMM at Exeter College.

The data above show that nearly all the people who came to the events had existing connections with autism and diagnosis of autism either personally or professionally. This is reflected in the motivations people gave for attending:

> "My 15 year old son with autism. I want to learn all I can to promote to the best possible life for him."
>
> "[I] felt that as a diagnostic service I should attend an event that explores the impact of diagnoses."

Alongside this, some of the attendees were drawn to the event because of their interest in the arts / filmmaking:

> "I'm an artist and filmmaker. Interest in films about social issues. Family mental health."

Everyone who responded (n=29) said they'd got what they wanted from the event but no-one ticked the "no" box suggesting some ambivalence to the question.

RQ1 Do the films help viewers to develop a more varied perspective on the effects of having a diagnosis of autism? Why?

Participant observation revealed that the Mainly Mozart, San Diego screening was part of a much larger conference which overtly framed autism in a positive light, celebrating neurodiversity and the strengths of autism. It is not surprising therefore that the films resonated with the audience at this event. The Cornwall Film Festival also had a small audience with several attendees being friends of Eddie (one of the artists who features in the films). The first event at Byrne House on the University of Exeter Campus had an invited audience of friends and collaborators of the project team due to this being the launch of the films. At Spike Island the audience, while smaller, was more diverse and were perhaps less primed for the messaging in the films.

Through the questionnaires, attendees were asked what they were thinking about after viewing the films and listening to the associated panel discussions.

The films and discussion clearly helped people think about the role and value of diagnosis, but didn't leave them with a firm position on the issue:

> *"Good to think about the complexity of the experiences of diagnosis."*
>
> *"Diagnosis - is this what people who are neurodiverse need?"*
>
> *"I'm thinking about the three films. How being diagnosed effects people differently. I am grateful to know Eddie and happy he is part of this project."*

For several people who responded to the questionnaire they were left feeling positive about being with others who wanted to see different representation of neurodiversity:

> *"How joyfully inspiring every artist, presenter, power parents and power professional is. I feel so many of us have come together to start a movement towards helping others see and experience autism in a whole new light."*

Some attendees were left thinking about how the films (rather than the ideas contained within them) had contributed to their thinking:

> *"The primary focus of celebrating difference. Have heard the words previously but having that concept demonstrated visually and with music has truly made the concept real for me."*

At these events, audiences also stated that they would take further action as a result of watching the films. These actions included:

- **Looking up more information about the strengths of autism spectrum disorder**: *"Will look up the paper on strengths in ASD."*
- **Share the films in a professional capacity eg when running training sessions for other professionals**: *"To check out the animations on Youtube"; "To go and look at the films on the website!"*
- **Share the films in a personal capacity**: *"I'd share the voices through the films and let them think about it all themselves."*
- **Inform their own experiences of living with and supporting people with autism:** *"I am inspired. I am hopeful. I want to expose my son to new things,*

more than what I am doing now. I want to celebrate his uniqueness and help him find his niche in this world."

- **To talk with others about the value of creative processes:** *"Creativity can help process struggles. Creating something expresses your problems could help you.", "How good animation is to explore these themes."*

RQ2 What was it about the process of developing the films that resulted in this?

The films were made through a participatory and inclusive process. People with autism were interviewed and their voices were edited into three films and artists with autism were commissioned to create the visuals. The artists were supported with training and support for making the animations. A cellist was commissioned to compose music to accompany the films after they were complete.

Capturing the experiences of living with, and having a diagnosis of, autism

The interviewees valued the interview process because if was enjoyable, a chance to reflect on their own life experiences and because it met the personal and professional ambitions of interviewees to raise awareness of autism and neurodiversity.

> *"Yeah, yeah. And I have loved coming to Exeter, and it's been great for my mental health to come here and get away from the craziness of East London. I think it's good to talk, because I have so much ... But it's hard to keep a structure in my head, because I go off in tangents all the time. But, no, it's been lovely, I've really enjoyed it."* P (at the time of being recorded)
>
> *"I've found it quite useful to be like ... it's given me a chance to look at things in a slightly broader perspective about my life and how autism has affected it."* J (at the time of being recorded)
>
> *"I think the interview's a positive experience to the extent that what I say is useful to other people. I've tried to dedicate my life to helping other people, and if I can say some things that are informative or reassuring or ... because I try to be accurate and not just say things to please people, or at least accurate about how I see things, because a lot of what I've talked about is not necessarily pure facts, but it's also evaluations."* S (at the time of being recorded)
>
> *"As an activist in the neurodiversity movement and autism researcher, I have helped diverse forms of media to portray autism in a more social than medical way as a*

> *complex difference to be supported, while trying to present evidence-based information. I knew the film would explore autism as a diagnosis and as an identity in line with the themes of the Exploring Diagnosis: Autism and Neurodiversity project, so I thought my expertise and perspective could be useful to it."* S (after seeing the films)

Having seen the films T reflected on why they had decided to participate in the work:

> T: *It was interesting. I like that my job involves around autism awareness, so that would help further that as well. I remember the questions being quite interesting and also my company told me to remain in good contact with the university, so it was also kind of part of my job as well. [Company name] wanted to keep good contact, so I was ambassador to the university... so as well as actually genuinely wanting to do it, it was also definitely a more interesting part of my job than anything else I had to do, but also I did want to do it on top of being required to do it.*
>
> HF: Yes, I understand. What was it about the questions that were interesting?
>
> T: *They were nice and open-ended [pause]. I could see the potential for definitely allowing people to open up. Yeah.*
>
> HF: Were they topics that you were familiar with talking about, so it was questions that you were like, 'Oh, yes, this is my comfort zone; I've talked about this before,' or was there something different to what you would normally talk about?
>
> T: *They are things I'd talked about before, but not things I talk about all the time, so it's [pause] things I had talked about and spoken about, but not so often that it's mechanical, and infrequently enough to see sometimes things do change in the meantime and additional perspectives are required. So things I have discussed, or at least, if not already discussed, then definitely thought about, but not so often that... it wasn't like doing my standard presentation for work over and over again. It was nice to re-tread those steps because they weren't steps that I had trod in a while.*

The artists valued being involved because it supported their artistic ambitions. Either by challenging their usual way of doing things as we see with AW here, or by extending a nascent interest as we see with E.

> *"I have found the project challenging, which is a good thing. It is different from what I normally do, because I hadn't done animation before. And also because thinking sequentially is difficult for me. I am a very non-linear thinker. It has been a good experience to begin to learn the medium of animation and to have to learn to think in that format, and see the possibilities of the format and for my art. Yes, I felt understood by the team."* AW

> *"I love learning and love a challenge. A friend had been encouraging me for some years to animate my sketchbooks and the idea had been on my mind even before that, to have a "living, moving painting." I had a friend who went to college for animation. I knew that I wasn't interested in traditional animation, such as a Disney film, but I liked experimental animation and art films, and I thought this would be a great opportunity to learn and to get involved in the process."* AW

> *"I was asked to take part and it looked interesting because I've always done some animation but needed to know more about it. I have taken part in a few little animation workshops and always liked it. I liked the fact that this was like a job and that I got paid for it because it meant I took it seriously and worked hard at it in my own time (with my creative worker)."* E

Film format

It was clear that the format of the messaging was valuable for some viewers. The film format which succinctly presented the lived experience of autism, and of diagnosis, was seen as affirmatory and refreshing.

> *"The primary focus of celebrating differences. Have heard the words previously but having that concept demonstrated visually and with music has truly made the concept real for me."* SD, Questionnaire

> *"I see my son in every slide, I closed my eyes and listened to every note. I feel gratitude."* SD, Questionnaire

> *"I just wanted to write and say how deeply touched I was by your films. I think they spoke with great clarity and eloquence. I wanted to cry all the way home! And that beautiful cello!"* email after launch event

Representation of living with autism and / or a diagnosis of autism

While the films were received positively by the intended audience this was not so universal for those people with autism we spoke with. On viewing the films, the people with autism described how they gave a good representation of living with autism and of having a diagnosis. They valued that the films showed multiple viewpoints which emphasised that not all people with autism are the same (or are likely to get on). But they also observed that the focus on art limited the representation of autism. Some participants felt that the films on their own were not sufficient for some audiences they would like to see engaged.

> *"I would have liked them to have been longer. They could have definitely been longer [pause] and maybe give each person a... Well, that comes under being longer, but giving more people more airtime. The editing is very, very good. The contrasting... there are a*

> *number of times when they contrast two different people perfectly, and I noticed there was one point where they contrasted me very... or what I... so there was some really nice editing for contrast. There... very nicely in... using the people of different... but the editing of the things that they were saying was really nice. That was really well done. It really could have been, to me, a bit longer just to go into my depth, just to maybe explain a little bit more to people who don't know…so it does help push across that whole, 'they're not all the same'."* T
>
> *"The film does an excellent job of incorporating my comments into the personal narratives, because she linked my description of being told my "brain was wired differently" after diagnosis to another interviewee's remark that it was a "comfort". I felt the same way… Therefore this experience was another lesson in learning to balance my identities as an autism researcher and an autistic person, an in communicating effectively to reach a community or general audience.*
>
> *The films made me feel excited to see autism represented as both a diagnosis and a way of being (a form of neurodiversity, if one wishes to think of it that way), as well as to see the work of autistic artists highlighted. I agreed with the sentiment expressed in "The State of Being Different" that autism diagnosis and identity or lived experience are quite separate, and that diagnosis may help with understanding or support but also pathologises and stigmatises people.*
>
> *I felt that the film accurately – from my perspective and the perspective of many other autistic people I know – represented autism as an experience quite different from its diagnosis, even though ironically the diagnosis has provided a platform for identities, services and supports, and research."* S (after seeing the films)

In the focus group there was some discussion about this:

> FG(M): *"I thought they were all really brilliant and I really liked that it wasn't stereotypical."*
>
> HF: Yes.
>
> FG(M): *"There was quite a few instances – I'll give you an example – like when they were talking about socialising and there was the one chap who really liked socialising with other people with autism and Asperger's...*
>
> [Agreement].
>
> FG(F): *And then in the next sentence, it was the girl saying, 'I hate it that everybody thinks that just because they have autism that we should get on.'*
>
> FG(F)**:** *So there was lots of things like that. That was really good.*

HF: Yeah, so it shows that it's not homogenous. It's not all the same, is it? Everyone's got a different experience, and that's the important thing to remember, isn't it?

[Agreement].

Presenting more than art

Because of the emphasis on neurodiversity, that the films only focused on art meant that some of the people interviewed suggested that it would have been appropriate to include a film about those who value science and numbers.

The emphasis on the art was also picked up by some participants as it did not resonate with them. There was a feeling either the art didn't reflect their taste, or could misrepresent the potential abilities of people with autism (as in T's quote below) or neglected to represent those people with an interest in science and technology (in the Focus Group quote):

FG(M): *"I think the fact that [art] was one-third of the whole thing bothered me, because there wasn't a short film afterwards about Aspies that like spreadsheets and stuff. ... there needed to be a fourth video or something, because it's not balanced.“* FG

"Because that one person that has no idea about Asperger's and autism at all, which is my intended audience, watches that and I think will get really good ideas from the first and third films and from the middle one they'll think, 'Oh, they're all into art.' FG

T: "*There are times when I'm not too sure about some of the artwork."*

HF**:** In what sense? Can you elaborate a bit more?

T: "*You might find it easier to draw more... people might not have to be as open-minded if the artwork was a little bit more direct. You could probably grab more people. I know they're trying to show off autistic artists, but maybe going a little... The art works nicely with the actual wording, but sometimes I could see it being a barrier to some people."*

HF: So if you're thinking back to who the audience is, that if it's about trying to present a broader understanding of living with autism, then perhaps the abstract nature of the art may not be as clear?

T: **"***A little too far, and also at times it's a little too childish, so it does look like something that a five-year-old did, so could impact negatively on how people view people on the spectrum, if they go, 'Oh, these autistic people can only make the art of five-year-olds.'"*

Focus group participants also highlighted that there are many other art forms that could have been represented, which they felt would have represented them and their experiences more directly. The participants discussed their woodworking skills, interests in photography and several other forms of creative practice.

Music

The music was singled out frequently in the comments. For some viewers it was beautiful, while for others it was challenging, in particular for the people with autism we spoke with. For these people cello music was quite surprising which created unease. Its sombre tone was also identified as a negative aspect of the films.

> *"Because I've got a thing with cellos. I don't like deep and dark sounds. I don't like it. I would only watch something like that if I am feeling emotional."* FG
>
> *"I felt that the music was contemplative and supported positive reflection."* S
>
> *"That beautiful cello!"* Questionaire

Additional support for the films

Finally, some participants felt that the intended audiences may need some support when watching the films to introduce the ideas in the films.

> T: "*I mean a parent who doesn't want to believe their kid's autistic, or someone who still... You'd need to warm them up a bit more before you could give them that."*
>
> HF: Yeah, I understand.
>
> T: *"But if they're already a little bit warm, that should finish the job, as it were. To use an analogy to cooking, you couldn't put somebody who was already frozen into that, but someone who had already defrosted, you could probably..."*
>
> T: "*So if you take someone who's just flat-out, 'My son's not autistic because autistic is a disease,' or, 'Autism is weird,' you're not gonna get anything out of that, but then again, you need something... But someone who has already defrosted and who genuinely wants to learn a little bit about what little Timmy's thinking or why little Timmy does x, y, z, yes, it'll be immensely useful. Yeah, they will have to be open. There is no way you could show that to even a slightly closed audience."*

RQ3 Did the project run smoothly and what can we learn from it?

The people who took part in the film-making through being interviewed or being commissioned to create the animations or being part of the broader project team, all found the process positive and rewarding. The films have been completed and screened a several times allowing us to identify that they do encourage people to think more deeply about autism, neurodiversity and the strengths and weaknesses of having a formal diagnosis.

The films were distributed through existing links and networks of the project team which reflect their interests in neurodiversity and art. It is therefore unsurprising that the audiences reached reflect these networks and subsequently resulted in them being "warm" to the ideas presented in the films.

The team have not undertaken a systematic distribution of the films to reach any or all of the project target audiences. The team could consider this as the next stage of this work: to identify distribution routes to reach larger numbers of eg health professionals, formal educators etc. It is likely that will not be a simple case of distribution, but a series of sustained engagement approaches that may involve workshops, articles and visits tailored for the target audiences and users to support them in thinking about how to use the films or the ideas presented in the films.

The original screening at Egenis, Byrne House on the University of Exeter, Streatham Campus was badged as an "autism-friendly" event. However, the group we spoke with found the event very uncomfortable. There was a lengthy and lively conversation in the focus group about the event at Byrne House during which it was noted that it was hard to find, too small, and the food was not appropriate.

Those who took part in the animation workshops (before the PE project and during) have all continued to use the animation skills and software.

> *"I use the software that was shown to me a lot now. I also use some of the things that the team (Dominic) showed me in my other work – for instance I am using some of the techniques shown to me in a new animation game that I'm making with my creative worker about my Autism, life and triggers. So it has been very useful.*" E
>
> *"The project meant I got better at doing animation and am more confident now. It also gave me more ideas – I may use animation in my next music video."* E

The focus group participants were going to continue to work on an animation they were in the process of working on, immediately after we finished the focus group.

One group of people the team worked with on making animations thought their work was going to be included in the finished films. When they arrived at the screening they discovered that this was not the case and were very disappointed.

> F: Another thing that I think everybody was a little bit upset about, especially J__, was that they took part in this animation and had lots of interviews...

M: We weren't in the videos.
F: And none of these guys' input was in any of the video.
HF: Was in the films.
F: Yeah.
HF: Okay.
F: And yeah, that wasn't made clear until it had already been organised...
HF: Until you were...
F: Until we were going down there and... yeah.
HF: That's a bit embarrassing and awkward, yes. Okay, all right, well that's... that's fine. [Agreement].
F: I think they would still have been interested to go and have a look, but they were expecting to see...
HF: See some of what they'd done, and that's understandable.
M: I remember when I was doing the animation, I did a lot of things with Lego mini-figures and I'm very proud of those.
HF: What, the films that you made?
M: Yeah, and I felt they would be incorporated into it, but nothing was... Unless you count our... if any of us were in those documents that came? I'm not sure.
HF: Yeah, I understand that.
M: The animation thing was really good.
F: Some of the interviews that you had, they would have taken out some of your ideas and inputs to help them towards making the films.
M: Okay.
HF: But it perhaps wasn't really clear to you what that link was. Yeah, that's all fair enough. I'm not surprised that was upsetting.

Conclusions and recommendations

The project has been positive and has broadly achieved its aims.

Three short films were produced with challenged current narratives about autism and the diagnosis of autism. Target audiences for the films were reached:

- Clinicians (e.g. speech therapists, diagnostic services, support workers working with those with learning disabilities)
- Researchers
- Autistic adults - both with and without diagnosis
- Parents of autistic children
- Friends and family of people with autism (with and without diagnosis)

Educators were also on the list of target audiences but were not identified as participating in the events that we evaluated. However, the films were opportunistically shared at a workshop at the BIG Event - the National STEM Communicators Network reaching a small number of informal educators. Educators in the form of academics were shown the films at internal events where members of the team felt it was relevant (eg the away day, Brocher Foundation residential retreat) and sixth form tutors were expose to the films at the STEAMM event in Exeter College. It was not possible to evaluate these events so it is not clear if/how these educators responded to the films.

Additionally, the films also attracted those with a primay interest in the arts, in particular social film-makers.

The intended outcome for the project was achieved:

“That viewers of the films have a greater awareness of the culture of diagnosis, identity and neurodiversity”

It is worth noting that those who responded to the questionnaires were already “warm” to the ideas being explored in the films. So it is perhaps more accurate to state the the viewers developed a more complex understanding of the culture of diagnosis, identity and neurodiversity. As the films did not reach beyond this warm audience it not possible to claim that they have achieved a numerical increase in awareness of these topics.

It is perhaps due to the lack of formal distribution plan that resulted in the viewers being small in number and already positive about the ideas being presented in the films. From this evaluation report we know that the films represent the experiences of living with and having a diagnosis of autism. We also know that they allow people to develop more complex views about these issues. From this it is possible to suggest that a broader distribution plan be developed, with associated engagement or support materials in place, for the different target audiences.

The team may wish to consider creating more films that represent those people with autism who have an interest in science and maths, and / or represent other creative pursuits, so that the suite of films more accurately reflects the broad interests of people with autism spectrum disorder.

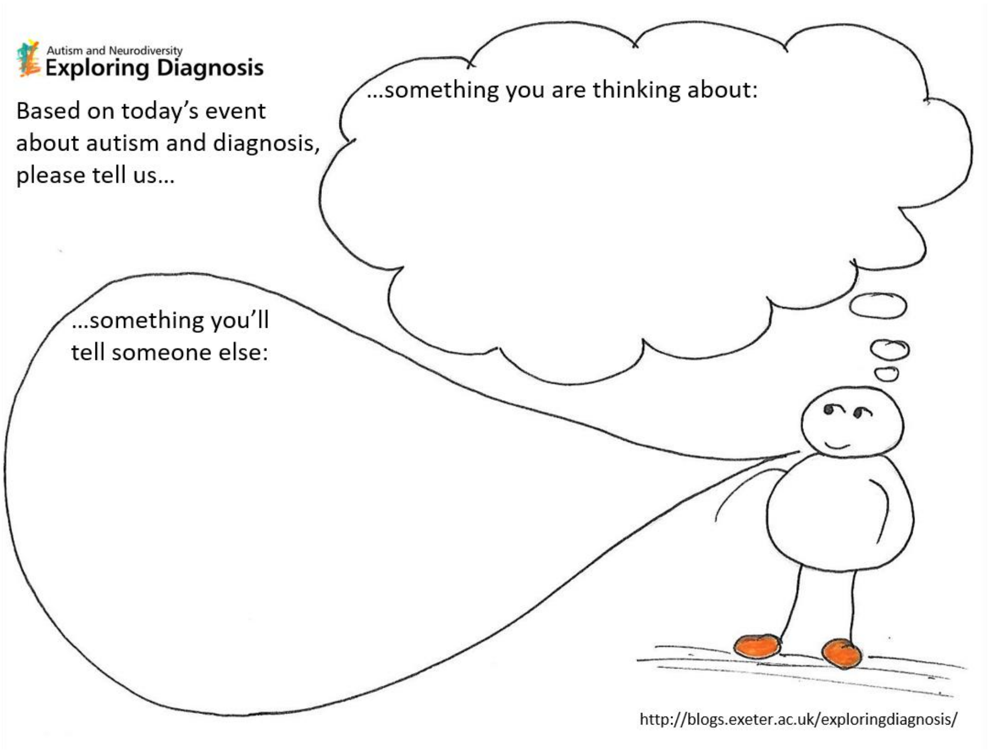
Audiences have found the process of making the films interesting.

To sum up:

- The participatory nature of making the films has been a very positive experience for those involved.
- The films represent perspectives on autism spectrum disorder and diagnosis of autism that resonate with people with autism spectrum disorder.
- Viewers of the films valued seeing autism spectrum disorder, and diagnosis of autism, presented from multiple perspectives.
- Viewers of the films were left with new ideas and more complex understandings of autism spectrum disorder, neurodiversity and diagnosis.
- Some viewers of the films stated they were going to do something having seen the films.
- The films have the potential to be useful in many settings and the team should consider a strategic approach to target some (or all) of the intended audiences.

Appendix 1 – Evaluation questionnaire

Front of the questionnaire postcard



Autism and Neurodiversity
Exploring Diagnosis

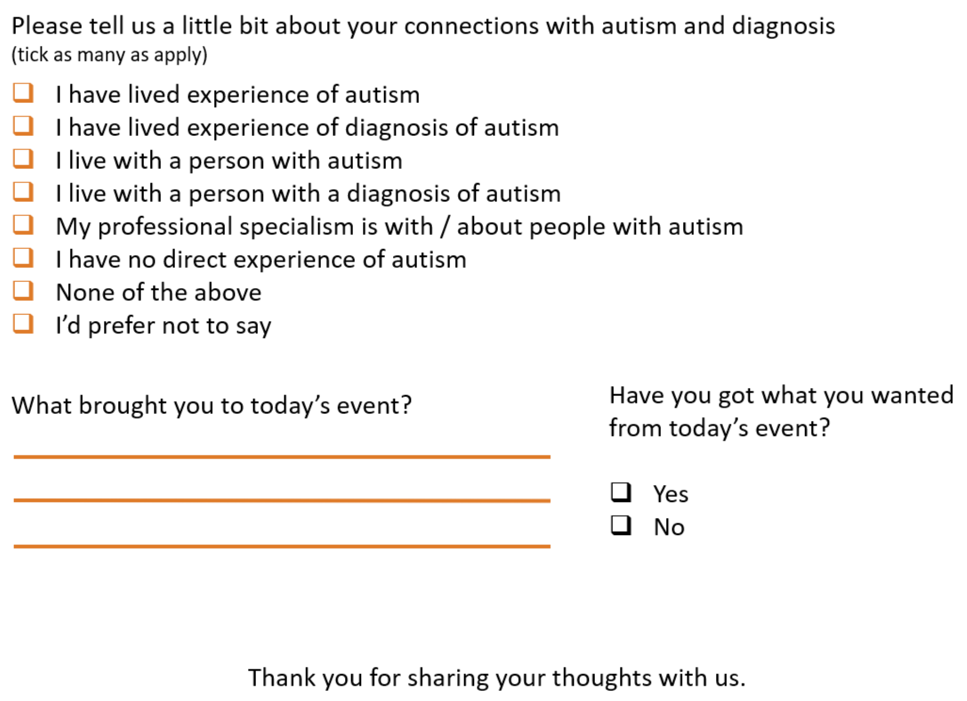
Based on today's event about autism and diagnosis, please tell us…

…something you are thinking about:

…something you'll tell someone else:

http://blogs.exeter.ac.uk/exploringdiagnosis/

Back of the questionnaire postcard



Please tell us a little bit about your connections with autism and diagnosis
(tick as many as apply)

- ☐ I have lived experience of autism
- ☐ I have lived experience of diagnosis of autism
- ☐ I live with a person with autism
- ☐ I live with a person with a diagnosis of autism
- ☐ My professional specialism is with / about people with autism
- ☐ I have no direct experience of autism
- ☐ None of the above
- ☐ I'd prefer not to say

What brought you to today's event?

____

____

____

Have you got what you wanted from today's event?

- ☐ Yes
- ☐ No

Thank you for sharing your thoughts with us.