

CHAPTER 6

Parent-Carer Film



Parent-Carer Film

"This film will lead the way
to changing the narrative."

- *Emma Durman*

Background

The Parent-Carer Film was launched on 1st April 2019. The National ASD Development Team's Leads inherited this piece of work when they came into post in 2018 which had been previously agreed with the Welsh Government.

The aim of the film was to complement the Parent-Carer hard copy Guide and the various films that the Team have created to increase awareness and understanding and provide advice to parents/carers, including the first Parent-Carer film, the Birthday Party film, and the Can You See Me? film.

It also derived from feedback from autistic people and other stakeholders who indicated that there was a gap in support in the period immediately following diagnosis.

Description

The Parent-Carer Film aims to support parents and carers with newly diagnosed autistic children. It is a resource that clinicians and professionals can use to signpost parents and carers to upon the child's diagnosis. It is also easily accessible online at the ASDinfoWales site:
<https://www.asdinfowales.co.uk/tv>.

The film covers a range of topics, including discussions with parents and carers, autistic individuals, and professionals.

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Approach

The National Leads wanted to change the format that had been previously agreed for the film, from a 'One Show' format, where a panel of professionals would discuss the various topics autism for the benefit of parents and carers, to a more holistic approach.

The National Leads wanted to co-produce the film with autistic young people and their parents and carers, and subsequently shift the focus of the film to be about their lived experiences and individual journeys that would capture the voice of autistic people and parents and carers.



Rather than following a script, the film was shaped by a series of conversations with people around autism and its impact.

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The Team facilitated individual interviews with autistic people and their parents and carers at a filming session, which was held for families in a bowling centre in Carmarthenshire. Further informal interviews took place in people's homes and informal settings.

Framing these clips of the autistic individuals and their parents and carers at the bowling centre was the panel, which followed the original 'One Show' format.



This section of the film sees the presenter, Trystan Ellis-Morris, asking questions to a panel comprised of one consultant clinical psychologist, a specialist speech and language practitioner, and two members of the National ASD Development Team, who discussed the resources available and the professional support and guidance that is available to all parents and carers across Wales.

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Challenges

The challenge of filming in this particular way also happened to be the most rewarding aspect of the work, which was to work alongside autistic people to co-produce something that would have been beneficial to them at the point of diagnosis. This approach can often be an emotional experience for all involved.

The approach also extended the time period that such a project can be undertaken within. There needed to be respect towards the diversity of all involved, and although it was often challenging trying to meet every participants' needs and views, the outcome was far greater. Emyr Jenkins, a member of the *Injan* filming crew that worked with the National ASD Development Team to create the film in such a pioneering way, had this to say:

“Whilst working with the National ASD Development Team on the Parent-Carer film, we all felt it was important to reflect the experience of real parents and carers who the viewers could identify with, and from there it was a natural step to also include the perspective of the young autistic people receiving their care. We're very proud of the way the film has allowed people to share their stories in order to help others in the same situation, and by adding to the mix the invaluable explanation and advice of experts and practitioners in the field, and bringing this all together in an easy-to-watch television-style format, we hope we've created a resource that will inspire parents and carers to seek out all the help that's available and to develop a positive outlook on the future, both for themselves and for the autistic children and young people in their care.”

- Emyr Jenkins

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It takes courage for people to be so truthful and open on camera, especially when the subject matter is such a personal one. As a Team, we want to continue to foster a culture where people respect this approach and to be mindful of what the individual has to say.

Outcome

When producing a film, it can be viewed in its entirety (in this case, 48:56), but also has value in being shown in short clips and sections to add to people's understanding of autism from a first-hand perspective.



Before the official launch of the film, the Team held a screening of the film so that all of the people who had been involved in the filming could see the end product before it was launched during **World Autism Awareness Week 2019**.



The feedback from the autistic individuals, their parents and carers, and professionals who took part in the film was overwhelmingly positive. Parents in particular felt that it gave a good introduction to parents and carers of newly diagnosed children, and also that it was exciting to hear the views of autistic people themselves in a positive and effective way.

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Comments Following The Screening

"I thought the film was really honest and to the point. Hopefully it will help people understand autism a bit better in the future... and if not, watch it again until you understand!" - *Luke Messaggio (autistic adult)*

"The film shows that there is a light at the end of the tunnel. It is informative because it covers all aspects, including the challenges, but it is also hopeful." - *Wendy Messaggio (Luke's mother)*

"As a grandmother, you feel for your daughter and what she's going through as well as your grandchild who is autistic – but the film gives hope." - *Annette Charles (Luke's grandmother)*

"My favourite part of the film was the body language of the people in it – you can see that some of us were nervous but we are all clearly having a good time and so it is positive without hiding the truth."
- *Mia Durman (autistic child)*

"The language used was perfect – it's not a 'disorder', it's a condition." - *Emma Durman (Mia's mother)*

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"Mia was nodding along while watching it, which shows how important it is for everyone to watch the film and be able to relate to it and see themselves in it." - *Phil Durman (Mia's father)*

"[The film] was very informative, and it will be very useful to parents with newly diagnosed children." - *Claire Evans (Issac's mother)*

"People will be able to dip in to the film. They will be able to relate to it."
- *Fiona Rogers (parent)*

"To involve families was imperative, because they are the experts. The quality of the film is excellent, and I loved the filming nights because people could relax together in a safe environment."
- *Amanda Roberts (Mencap Cymru)*

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On the day of the screening, as well as the day of filming at the bowling centre, autistic individuals were granted a “safe space” to enjoy, be themselves, and celebrate their autism.

The Team continuously strive to provide opportunities for individuals to get involved and experience such joy. For example, one of the autistic delegates performed his favourite songs at the screening. It was exhilarating to see a young autistic man perform with such talent, especially as he had been non-verbal until he was 8 years old.

It is important to let autistic people have the same opportunities as everyone else.

Usage

Following the launch of the film, the Team will now go on to update the parent-carer guide that the film is based upon.

To rollout the film, it will be publicised across the Children’s Neurodevelopmental Services and shared across the Team’s stakeholders.

The film will also be broken down into smaller sections in order to be easily accessible by topic.

Lessons Learned

It takes far longer to co-produce work projects with “real people” but it is certainly worth doing, and the Team are committed to continuing with this meaningful and successful approach.