

Exploring Onstage Portrayals of Parent/Carers of Disabled Adults/Children

Internship Report

Dr Nina Worthington - August 2023

Background

This internship was held within the Sidney De Haan Research Centre for Arts and Health (SDHRC). SDHRC have undertaken a series of research projects relating to arts, health, and disability. The most recent explores experiences of disability among NHS staff at the Royal Orthopaedic Hospital in Birmingham, my own PhD work explored lived experiences of disability in theatre industry. One emergent strand of this work is the impact of arts-based initiatives, crossing disabled and non-disabled communities, in challenging disability stereotypes and discrimination. These studies point to how promoting accurate, public narrative, expressed through the arts, and based on lived experiences of disability, is crucial in countering longstanding societal misunderstandings of disabled people. The initial intention of the internship proposal was to take this research further, to consider how public portrayals of the lives of carers/parents of disabled people also shapes perceptions and how families of disabled people might be key allies in challenging societal misunderstandings of disability through the arts. The project focused on a literature review aimed to overview onstage portrayals of parents/carers of disabled people in modern theatre. It was intended to prepare the ground for participatory research that will encourage a series of conversations between decision-makers in theatre who have lived experience of disability in their families. The outcomes of this research have begun to utilise existing research in a way that could prepare for a future bid in this area.

The Internship

Emily Fawsitt, a final year drama student at CCCU, was appointed to the internship in April 2023. Due to final assessment deadlines and personal issues, Emily was only able to complete 41 hours work on the project. 159 available hours remain. The internship outcomes can be seen in the following table:

To complete a literature search	Emily was introduced to an electronic research strategy and created an annotated bibliography using excel. This begins to highlight books, academic journal articles, and news articles that are potentially relevant documents. This will be a starting point for identifying key literature drawn on a in future participatory research proposal.
To search existing literature for comments and thematic analysis	Emily was given training with library support staff on how to search a collection of e-journals and databases. She was also given training on systematic recording of citations and coding literature for thematic analysis.
To identify real life narratives of parents/carers and potential networks of parents/carers in theatre	Due to limitations on Emily's time, we decided to keep the focus on a CCCU library search not widen this to consideration of online debate in blogs, reviews etc.
To contribute to paper for publication	Realising that Emily was unable to commit to the full internship, it was not possible to consider a co-authored

	publication despite this being useful on her curriculum vitae. It is still possible researchers with SDHRC could complete the review leading to publication.
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Benefits

In conversation with Emily, as a drama student uncertain of the next step in her career, we feel that there have been several benefits to her from the internship:

- the opportunity to see how a University Research Centre works. Emily was invited to informal meetings with the SDHRC team and attended the FMHSC research event, which included the SDHRC showcase. Emily was able to ask questions about opportunities for further study and future academic work.
- developing library and literature search skills.
- developing strategies for structuring a literature review, using excel, and coding for thematic analysis.
- increasing personal awareness and knowledge of disability theory, history, politics, and cultural representation.

There were also several benefits to SDHRC from this internship:

- the beginnings of a bibliography that will form a helpful tool towards creating a future participatory research bid and opening scope for a larger funding bid for industry-based research.
- Identification of literature which confirms gaps in existing research.
- having a fresh voice to join some of the research conversations in the centre and about potential for this research, adding a new perspective.

Limitations

It would have been ideal if this internship could have started after Emily had completed her final degree assignments. However, there were additional factors related to Emily finishing at university that also altered the commitment she was able to give to this project. We were flexible with the outcomes of this internship when we realised Emily's situation and priorities had changed. Unfortunately, this did not make it possible to complete the in depth review we had hoped to achieve. Revision of the timing of future RKE internships may have a beneficial impact on the commitment interns like Emily are able to give.

Intended Next Steps

We would like to use the beginnings of this literature review to identify key texts to provide a stimulus for open conversation, based on lived experiences, with parents/carers of disabled people. We would like to use the outcomes of this internship to support a participatory research bid that will gather a network of theatre makers who are also parents/carers. As highlighted in the beginnings of this literature review, multidimensionality is lacking in public narrative surrounding the lives of parents/carers; theatrical representations of what is experienced in caring for a disabled person are narrow, offering little challenge to damaging stereotypes of disabled people. The beginnings of this literature review are a step in considering how to enable the creation of

new public narratives that accurately reflect parents/carers real lives, moving beyond narratives of disability as only loss, pity, shame, and hopelessness. We hope this will inform a proactive response in which real life stories of parents/carers can help shape diverse representations of disability that support the health, wellbeing, and social outcomes of disabled people and their families.