



**LA TROBE**  
**UNIVERSITY**  
AUSTRALIA

**'Is it a bird? Is it a plane? No way! It's me becoming a super-advocate! Exploring student-parent experiences of a postgraduate disability studies programme.**

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## some background...

- **La Trobe University has offered postgraduate courses in disability studies called 'Disability Practice' since 2018**
- **Response to shortages of skilled workers in the sector**
- **Targeting early to mid-career professionals with tertiary qualifications in teaching, nursing, social work, psychology and other allied health disciplines.**
- **Attracted people new to the sector and people with decades of experience**
- **Subjects on inclusion, advocacy, ethics, law, complex needs, disability policy**
- **A significant number of students are parents of people with intellectual disabilities**

# disability studies as a discipline

**“...disability studies is a broad arena of theory, research, activism and practice that contests the popular view that disability equates with human failing.”  
(Goodley, 2016)**

**Disability studies courses can have a ‘positive effect’ on the lived experience of people with disabilities by placing disability issues in their ‘social, cultural and political context.’ (Taylor, 2011),**

**“...putting people with disabilities and their leadership at the centre of policy and practice.” (Buffington-Adams & Vaughan, 2019).**

**“... a ‘vehicle’ for the critical examination of questions about all aspects of community life... and an opportunity to make ‘new meanings about disability’ with the goal of empowerment (Ferguson & Nusbaum, 2012)**

**When students engage with a disability studies curriculum, they ‘join the human rights discourse’ (Van Hove et. al, 2012)**

# Pearson et al (2016)

- **Study of post graduate disability studies students who were education professionals**
- **Disability as 'social, cultural and political'**
- **First exposure to non-medical conceptualisation of disability**
- **Students described the experience as 'transformative'**
- **Students wanted to change their practice and focus on social justice and addressing exclusion**

## Vaughan and Super (2019)

**“...the ideas and theories of Disability Studies can alter how parents understand and act in relationship to their children and larger systems”**

**There is no published evidence which supports or refutes this proposition, but...**

**If disability studies and disability-focussed programmes can positively impact the support and advocacy activities of student-parents, then it is hoped that there may also be positive impacts on the quality of life of their family members with disabilities.**

## research questions

- **How do student-parents experience a disability studies curriculum?**
- **Is the critical realist approach to disability which underpins this course meaningful to student-parents in their support and advocacy roles?**
- **How do student-parents plan to use knowledge and skills gained through disability-focused study?**

# methods

- **Small scale exploratory study**
- **Human ethics approval**
- **Convenience sampling with third party recruitment**
- **Sample size of 6 student-parents**
- **Semi-structured interviews**
- **Thematic analysis from Braun & Clarke (2006, 2017)**
- **Participants have been given pseudonyms**

# findings

**Four key themes emerged from the analysis of the results:**

- **Fitting study into busy lives**
- **Speaking a new disability language**
- **Putting 'choice and control' first**
- **Becoming a super-advocate**



# theme 1: fitting study into busy lives

**It's a lot... but sometimes an oasis**

*All my sons are living at home...I'm on the night shift and mostly the day shift...lots of medical appointments...it's pretty full on...some study as well, why not? Tracey.*

*The subjects are great it's just...it's a lot on top of work and family... Jeff.*

*The study has been like an oasis...a break for me from thinking and worrying endlessly about all the things that need to happen, things I have to get done in our family...these are crazy times! Jenny.*

*Doing the course and being back at uni is a luxury...it breaks up the time, it feels different from all the crap going on...it's fun. Luke.*

## theme 2 : speaking a new disability language

*It's like learning a new language...disability language... to describe concepts using more...complex ideas and words...I can use the research I've learned about which goes with each topic to speak about disability in a new way. Ruth*

*You know I'm not going to throw those words 'critical realism' into any conversations [laughs] but those ideas do mean something to me and they help me to make sense of some of the policies and programmes I've been studying. I can talk the talk!! Jeff.*

*It's not relatable. If I tried to have a conversation about models of disability...I might as well be speaking Greek but I can use the knowledge. Tracey.*

## theme 3 : putting 'choice and control' first

*Every single unit I've done so far is about putting the choices of the person with a disability front and centre. Ruth.*

*The advocacy subject was so great for reminding over and over that when decisions are being made that if you're a Dad or a support coordinator or whatever then what the person wants is the number one thing to be thinking about...managing other conflicts of interest, all that... but it's the person and what they want... Luke.*

## theme 4 : becoming a super-advocate

*The course has given me a lot of confidence I think. I can write much better emails that's for sure! I have ammunition now and that confidence to say that's not what she [daughter] wants... Jenny*

*Of course the NDIS is an improvement on what was there before but it's been an epic battle to get her plan right and I often think gee if she didn't have her parents in her corner fighting all the time...The studies have been good...I feel I've got some extra knowledge on my side...Luke.*

*I have been an advocate for my daughter since she was born... I'm sure people hear its me on the phone and roll their eyes...it's that bloody woman [laughs] Is it a bird? Is it a plane? No way! It's me becoming a super-advocate! Ruth*

## what has changed?

*I really had spent a lot of time focussing on the medical stuff probably because as a family so much focus has been on doctors and therapy and such things...through the subjects...reading about social stigma, inclusion...or should it be excluding... discrimination ...thinking now about that whole person and their life, all of it. Jeff*

*It was shocking to read about institutions and even how recently they have been used to hide people away...a lot of people probably me included, thought that some of the paternalistic...some of the medical treatments, therapies and locking people away was 'care' [gestures inverted commas] but its now so clear that peoples' human rights need to come first and with the NDIS thinking about choice... there's a chance for things to improve. Jenny*

# discussion

- **Study is expensive and a major time commitment**
- **An 'oasis' for some**
- **Exposure to new material, research and theories was enjoyable and challenging**
- **Links were made by the participants between contemporary understandings of disability and the NDIS**
- **Advocacy featured in comments by all of the participants**

## conclusion

- **Small scale pilot study of students from one programme**
- **Some evidence of Vaughan and Super's (2019) proposition that engagement with the concepts and theorising in Disability Studies programmes can alter the knowledge and actions of students who are parents of people with disabilities.**
- **There is no evidence about the 'actions' of the student-parents beyond their descriptions of their interactions with planners and service providers.**
- **The potential of disability studies to empower advocacy is strongly reflected in the results of this study.**
- **More than an intellectual exercise...**

# references

Albanesi, H. P., & Sauer, J. (2013). Questioning Privilege from within the Special Education Process. *Understanding and Dismantling Privilege, 3*(1).

Australia. Department of Social Services. (2021). NDIS National Workforce Plan: 2021-2025.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589–597.

Buffington-Adams, J., & Vaughan, K. P. (2019). Introduction: An invitation to complicated conversations. *Journal of Curriculum Theorizing, 34*(1).

Church, K. (2015). 'It's complicated': blending disability and mad studies in the corporatising university. In *Madness, distress and the politics of disablement* (pp. 261-270). Policy Press.

Coughlin, A. B. (2021). Education is power: But only if you can get into the building. In D. J. Connor & B. A. Ferri (Eds.) *How teaching shapes our thinking about disabilities: Stories from the field* (pp. 249-262). Peter Lang.



# references

Estes, D. K. (2011). Managing the student-parent dilemma: Mothers and fathers in higher education. *Symbolic Interaction, 34* (2), 198-219.

Ferguson, P. M. & Nusbaum, E. (2012). Disability studies: What is it and what difference does it make? *Research and Practice for Persons with Severe Disabilities, 37* (2), 70-80.

Goodley, D. (2016). *Disability studies: An interdisciplinary introduction*. (2<sup>nd</sup> ed.). Sage.

Jackson, A.J. (2021) *Worlds of care. The emotional lives of fathers caring for children with disabilities*. University of California Press.

Meekosha H. & Shuttleworth, R. (2009) What's so 'critical' about critical disability studies?, *Australian Journal of Human Rights, 15*:1, 47-75, DOI: [10.1080/1323238X.2009.11910861](https://doi.org/10.1080/1323238X.2009.11910861)

NDIS (2023) *Supported decision making policy* <https://www.ndis.gov.au/aboutus/policies/supported-decision-making-policy> NDIS

Ong-Dean, C. (2009). *Distinguishing disability: Parents, privilege, and special education*. University of Chicago Press.

Pearson, H., Cosier, M., Kim, J. J., Gomez, A. M., Hines, C., McKee, A. A., & Ruiz, L. Z. (2016). The impact of Disability Studies curriculum on education professionals' perspectives and practice: Implications for education, social justice, and social change. *Disability Studies Quarterly, 36* (2).

# references

Shakespeare, T. (2013). *Disability rights and wrongs revisited*. Routledge.

Taylor, S. J. (2011). Disability studies in higher education. *New directions for higher education*, (154), 93-98.

Van Hove, G., De Schauwer, E., Mortier, K., Claes, L., De Munck, K., Verstichele, M., ... & Thienpondt, L. (2012). Supporting graduate students toward "a pedagogy of hope": Resisting and redefining traditional notions of disability. *Review of Disability Studies: An International Journal*, 8 (3), 45-54

Vaughan, K. P., & Super, G. (2019). Theory, practice, and perspectives: Disability Studies and parenting children with disabilities. *Disability & Society*, 34 (7-8), 1102-1124.

**thank**

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