



GROWING
UP
DISABLED
IN
AUSTRALIA

EDITED BY CARLY FINDLAY

Teaching Notes by Christine Davey-White

Teaching notes

BY CHRISTINE DAVEY-WHITE

THEMES

- ◆ Identity and ownership of narrative voice
- ◆ Voice and ownership of the disabled story
- ◆ Converging and intersecting identities
- ◆ Evolving social consciousness
- ◆ Defying systemic low expectations
- ◆ Impact of the othering narrative
- ◆ Language

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Part A

Synopsis and editor biography

SYNOPSIS

Growing Up Disabled in Australia, edited by Carly Findlay, reflects the intersectional nature of disability: the anthology presents readers with the lived experiences of disabled people across cultural, generational, and socio-economic *subgroups*. Australia is still evolving in its response to the psychosocial needs of minority groups, and growing up in such a country as a member of a minority group can be difficult. *Growing Up Disabled* is based on the social model of disability – which views the obstacles society creates for disabled people as the problem, rather than

the impairment, illness or disability itself. The changing ways disability is understood in Australia have resulted in many disabled people now seeing disability as an important part of their identity. The stories in *Growing Up Disabled* reflect this shift and explore how views of disability have changed over time.

Carly Findlay is an appearance activist, writer, speaker and fashionista. She has been blogging for over a decade, and published her memoir *Say Hello* (HarperCollins Publishers) in 2019. She also contributed to *Growing Up African in Australia* (Black Inc., 2019), as well as writing for various media publications. Carly also works for the Fringe Festival and in 2018 organised the inaugural Access to Fashion event. Carly grew up in Albury but has since made her home in the western suburbs of Melbourne, Victoria.

PART B

Pre-reading tasks

Before reading, consider these notes from editor Carly Findlay about ways to discuss *Growing Up Disabled*:

- ◆ ‘Disability’ and ‘disabled’ are not bad words. It’s appropriate to write or say either ‘people with disability’ or ‘disabled people’. Stigma is created when euphemisms such as a ‘special needs’, ‘diffability’, ‘differently abled’ or ‘additional needs’ are used.
- ◆ The book is based on the social model of disability. That is, disabling barriers are caused by society, not people with disabled bodies. These barriers are physical, attitudinal and systemic.
- ◆ It doesn’t matter how we got like this – sometimes we don’t need to tell our disability backstory for our current story to be powerful.
- ◆ Use empowering language. Words like ‘wheelchair bound’, ‘suffers from’, ‘normal’ and ‘overcoming’ are disempowering and othering. Use ‘wheelchair user’, ‘lives with’, ‘non-disabled people’ or ‘people without disability’ instead.
- ◆ Avoid inspiration porn. Inspiration porn is the objectification of disabled people for the benefit of non-disabled people – positioning our lives and bodies as either tragic or inspirational. For more on inspiration porn, see Stella Young’s TED talk: https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much
- ◆ For further information, visit People with Disability Australia’s reporting guide. <https://pwd.org.au/resources/disability-info/language-guide/reporting-on-disability/>

You may also wish to do some research about:

- ◆ the language of disability and how it has changed over time
- ◆ Spoon theory
- ◆ visible and invisible disabilities and chronic illness

- ◆ the medical model of disability versus the social model of disability
- ◆ a lived-experience approach to discussing disability versus a parent-centric approach
- ◆ the role of parental advocacy in change
- ◆ the role of disability activism in enacting community change
- ◆ intersectional issues related to accessing support
- ◆ the Royal Commission into the violence, abuse, exploitation and neglect of disabled people in Australia
- ◆ ableism.

PART C

Questions to provoke discussion and thinking while reading

‘QUESTION MARKS AND A THEORY OF VISION’

BY ANDY JACKSON

- ◆ How does the language of the second paragraph centre the reader in the Australian landscape?
- ◆ How does Jackson show the way society ‘others’ disabled people? Consider the imagery and language used and how this is juxtaposed with Jackson’s depiction of his own life.
- ◆ Consider the way Jackson starts to use the ‘othered’ language to describe himself and his own experience. How does he use *italics* to separate himself from disability? What idea is he showing about how disability is seen in society?
- ◆ What does Jackson show about the world’s inability to see him? How does it link to his discussion of *Plato’s theory of vision*?
- ◆ What is it that Jackson sees about disability that he wishes others could see?
- ◆ How does the symbol of the question mark mimic the descriptions he provides for his spine?
- ◆ What answers has disability provided Jackson?

‘FOREVER FIXING’ BY EL GIBBS

- ◆ How does Gibbs instantly make the reader realise that the disability community has been largely unseen by society?
- ◆ Gibbs describes herself as ‘recalcitrant’. Recalcitrant to whom? And what is Gibbs saying about this group’s mindset? See Gibbs’ description of this group ‘berating’ her.
- ◆ What is Gibbs showing the reader about the medicalised nature of disability? What is the impact of this mindset on an individual? Discuss the relentlessness and sense of failure that is provoked by this way of thinking.

- ◆ How did Gibbs transition from being ostracised by her disability to becoming a part of a community?
- ◆ How could her epiphany help others who find themselves struggling as she did earlier in her life?

‘SELECTED EPISTLES’ BY OLIVIA MUSCAT

- ◆ How do Muscat’s letters wrench back a level of control over the way she is treated?
- ◆ What do the letters show about the way the community belittles and infantilises disabled people?
- ◆ Why is it important for the reader to see the Drama teacher’s opinion and behaviour evolve?
- ◆ What is the importance of *Jemima’s* role in Muscat’s life?
- ◆ What boundaries is Muscat setting in her letters? How do the letters suggest these boundaries have been crossed numerous times (and with what effect)?
- ◆ What do Muscat’s letters reveal about the barriers experienced by disabled people, and the attitudes of society towards them?
- ◆ How do Muscat’s *letter closings* reflect the way she wants the recipient to see her? What relationship is requested by Muscat in these sign-offs?
- ◆ How does Muscat’s letter to her mother demonstrate parental advocacy without reducing an individual’s agency?

‘LAKE NASH’ BY DION BEASLEY AND JOHANNA BELL

- ◆ How does the language used by the authors present a unique voice that shows Australian Standard English was not the first language Dion learnt?
- ◆ What does the narrative voice say about how Dion interprets the world?
- ◆ How does the staccato style of language immerse the reader in Dion’s world?
- ◆ How does the narrative show the sense of belonging Dion finds within the family unit?
- ◆ How does the language demystify and de-romanticise the disabled narrative?
- ◆ How does this narrative differ to those normally told about disability? What message about disability does it convey?

‘THE ELEVENTH HOUSE’ BY SAM DRUMMOND

- ◆ The series of surgeries Drummond describes are bookended by the event involving Maggie. What does Maggie’s death symbolise to Drummond?
- ◆ The photos are interpreted differently by Drummond and others. What does this say about the emotional turmoil and confusion he is going through?
- ◆ How is the feeling of division and separation from community Drummond experiences represented by the other houses being on the ‘right side’ of the street?

- ◆ Drummond speaks of himself as an ‘opportunity’ for doctors and medical students. How does this reflect the way disability is often seen by the community, and what impact does this have on Drummond’s sense of normalcy?
- ◆ How do Drummond’s political references track shifts in society’s ‘othering’ of marginalised groups?
- ◆ ‘The world did not answer.’ What fate had Drummond accepted? How does it relate to his place in the world and the disability he lives with?
- ◆ What intersecting issues are suggested in Drummond’s text, and how did they shape his lived experience?
- ◆ Consider the importance of House Eleven. How and why does the narrative change pace at this stage?
- ◆ How does the narrative represent a coming of age, and a realisation of the harshness of people and the world?

‘WIRED FOR SOUND’ BY FIONA MURPHY

- ◆ How do the hearing glasses symbolise the transition from invisible disability to visible disability?
- ◆ The audiologist thinks Murphy will be excited about the hearing glasses, but instead she displays trepidation. Why?
- ◆ Discuss the way the weight of the glasses is both symbolic and literal. Why does Murphy feel ‘unencumbered’ when sleeping?
- ◆ How did society restrict Murphy’s access to the language of learning? How did she eventually access this world?
- ◆ What version of herself did the hearing glasses represent to Murphy? How did she feel about this?
- ◆ How and why has Murphy morphed from not liking the visible elements of her disability to purposely making her Deafness visible?
- ◆ What can we learn from the story Murphy tells about her English teacher?

‘HIPPO THERAPY’ BY ALISTAIR BALDWIN

- ◆ What does this story show the reader about the importance of connection and shared experiences?
- ◆ What is being said about the *hidden away* nature of disability programs?
- ◆ What evidence can you find that Baldwin internalised an ableist mindset (even if he jokes about it)?
- ◆ ‘All you do is compare yourself to your friends and bullies.’ How does Baldwin’s assessment show the way ableism is entrenched in our society?
- ◆ How does Baldwin use humour to buffer the pain of being part of a marginalised community?
- ◆ Why does Baldwin feel an affinity with the horses? Discuss the link between ability and perceived worth to society.
- ◆ What does Baldwin say was the ultimate benefit of the horse-riding program?

‘LIFE GOES ON’ AND ‘THE BLUE ROSE’

BY KERRI-ANN MESSENGER

- ◆ What is the importance of the writer’s note at the beginning of each text?
- ◆ In ‘Life Goes On’, Messenger talks of a life standing still. What parts of life are moving on, and what parts are stagnant (and for whom)?
- ◆ What does ‘Life Goes On’ suggest about the lack of agency Messenger felt in her life?
- ◆ What perception of an institution does Messenger present ‘Life Goes On’? How does she portray herself?
- ◆ From reading ‘The Blue Rose’, what sense do you get of how Messenger regards herself?
- ◆ What clues in the text suggest Messenger hasn’t always heard the narrative presented by the second nurse?
- ◆ Compare the poems. The first is filled with sadness, and the second with assertive determination. How does the juxtaposition present a narrative about how disability is viewed in society?
- ◆ Do you feel what ‘we’ feel? Do you feel what ‘I’ feel? How does this repeated question prompt the reader to see disability through a new lens?

‘FALLING IN LOVE, FANFIC, AND BONE FUSION’

BY KIT KAVANAGH-RYAN

- ◆ Kavanagh-Ryan’s text addresses the infantilisation of disabled people, in that they have often be desexualised. With this in mind, what did Kavanagh-Ryan’s mother possibly mean when she said, ‘*Kitty, you’re making things terribly hard ...?*’
- ◆ “‘You can’t be lesbian *and* disabled,’ she wailed.’ Why is the ‘*and*’ italicised? What does this say about the understanding people have of disabled people?
- ◆ What does the integration of internet speak in her piece tell us about Kavanagh-Ryan’s life?
- ◆ How does Kavanagh-Ryan describe the way the online world and the real world overlap, and how does each space differ as a space for disabled people?
- ◆ Why does Kavanagh-Ryan both despise being matched up with Annie, and feel a protective affinity for her? What should we learn from this?
- ◆ What impositions does Kavanagh-Ryan find in the hospital?
- ◆ Kavanagh-Ryan wants a ‘*seat at the table*’. Who else is sitting at this table and what does she have to tell them?
- ◆ What perspective do the parents in this story share? How does this differ from how Kavanagh-Ryan views her experience as a disabled person?

‘NOISY SILENCE’ BY ANNA WHATELEY

- ◆ Whateley’s text has an epistolary element, followed by a reflective commentary. How does each reflection shed light on the events presented in the preceding part?
- ◆ Whateley’s earliest entry is from her five-year-old self. What is the prevailing memory she is left with, and how could this impact her acceptance of her disability?
- ◆ The first three entries mention Whateley receiving physical reprimands for her behaviour. What does this tell us about the way disability is sometimes dealt with in our society? How do these events reflect a wider violence in Australian culture?
- ◆ Whateley compares how she would be treated ‘now’ (if she were at school today) with how she was treated and labelled as a child. What does this reveal to the reader?
- ◆ How does Whateley’s diary entry (aged thirteen) reflect the long-term impact of how she was treated as a child?
- ◆ What does Whateley’s rejection of the ‘*mermaid*’ analogy, and reclamation of the term ‘*merfolk*’ show the reader about the expectation that disabled and chronically ill people conform to society?
- ◆ What was the ‘*cost*’ of passing as neurotypical?
- ◆ What trauma does Whateley suggest comes with growing up disabled?

‘YOU ARE ENOUGH’ BY JORDON STEELE-JOHN

- ◆ How did the intergenerational nature of Steele-John’s family unit create a world removed from the one many disabled people experience?
- ◆ How did Steele-John’s early life provide the resilience needed to tackle the wider community?
- ◆ Steele-John says, ‘... *I’ve not been medicalised.*’ How does this differ from other narrative voices the reader is exposed to in the anthology, and why has he emphasised the importance of this fact?
- ◆ Steele-John describes a positive upbringing that he eventually labels a ‘*self-delusion*’. What is this self-delusion he speaks of, and why is it so important that he addressed it?
- ◆ What is the importance of a ‘*collective community*’?
- ◆ Steele-John uses his position to highlight the way disabled people have been marginalised and excluded from sharing public spaces. What long-term changes are needed in the community mindset to ensure everyone has a voice and feels welcome?
- ◆ What do the accessibility issues at Parliament House suggest about the expectations the community has for disabled people?
- ◆ Steele-John sees the Royal Commission in the violence, abuse, exploitation and neglect of disabled people in Australia as ‘*an opportunity for truth and justice and storytelling ...*’. What stories will be told, and what does Steele-John want society to learn?

‘I DON’T NEED THEM TO SEE THROUGH YOU’

BY JESSICA KNIGHT

- ◆ The glasses become a motif that highlights the way society views disability. How does this symbolise the inability to accept the need for people to use visual and other disability aides?
- ◆ Consider society’s perceived inability to see sexual worth in disabled people. How is this notion reflected in the continued requests for disabled people to remove their disability aides to increase their sexual worth?
- ◆ How do disability and visual aides become a part of how the person sees themselves? What does Knight show about the importance of being proud of the aide?

‘DECEMBER THREE’ BY C.B. MAKO

- ◆ *‘My story is not the story ...’*. What sort of story does society expect from a disabled person?
- ◆ What role does the formatting of this text have in giving the reader a sense of Mako’s narrative voice? How does the formatting retain control for the author, and why might this be important?
- ◆ Mako mentions *‘duality’*. What struggles come with this duality, and what does the text suggest is the cause of this?
- ◆ What is shown to be a prevailing viewpoint that society has of disability, and how is this shattered by Mako’s discussion of sexuality?
- ◆ What barriers does Mako share in the text? How can these systemic features of life restrict the types of narrative voices society can hear?

‘NEVER NEEDED FIXING’ BY ELIZA HULL

- ◆ The first line of the text suggests the language used about disability is the most impactful. What language does Hull refer to, and how can it affect the disabled individual?
- ◆ *‘Medical staff constantly talked about me, not to me.’* What is the result of not being truly seen by those who are treating you?
- ◆ Hull details a constant expectation to be ‘fixed’. What does this show about society’s perception of disability, and how does this sort of narrative alter the view she had of herself?
- ◆ What does Hull’s story say about the impact of being told that disability is a deficit? How does this compare to her adult identity?
- ◆ What is important about the title? Who is this title for?

‘HAVING A VOICE’ BY BELINDA DOWNES

- ◆ What does this text suggest about the power of knowledge and information, and what role does this play in a disabled person’s life?
- ◆ What is being said about who holds the power and knowledge?
- ◆ What assumptions about disability does Downes’s piece highlight?

- ◆ What does Downes's piece show about how pop culture perpetuates inaccuracies about disabled people?
- ◆ Why was it such a 'victory' the surgeon had 'heard' Downes? What was the alternative scenario and, had it occurred, what would this have told Downes?
- ◆ The reader may interpret the motivations for Downes's mother's actions as ableist – wanting to fix the child – but when the actual reason is revealed it shows a deeper issue that some disabled people face. What is this issue and how might it be enabled by society?
- ◆ *'It's this fraud that has had the biggest impact on my life, not my scars.'* Why would Downes feel the need to explicitly state this?
- ◆ How does having your own agency and control change the parent-child dynamic? Why do children need help to find and use their voice?

'CHLOROPHYLL LIKE PINK' BY PATRICK GUNASEKERA

- ◆ How does the frenetic pace of the narrative allow the reader insight into Gunaskera's lived experience?
- ◆ Gunaskera feels the pressure of competing societal expectations – what are these and how do they intersect?
- ◆ Gunaskera has a unique vernacular that showcases the intersecting identities he embodies. How does this language show the strength in his identity and represent the 'othering' he experienced from society?
- ◆ *'Spoons too low ...'* and *'... how are you for spoons ...'* What exactly is meant by these phrases? How does Gunaskera show the importance of having connection with others using this culturally specific language?
- ◆ Gunaskera writes about *'being own hero.'* What sort of hero does Gunaskera represent, and why does he need this?
- ◆ How and where does Gunaskera find acceptance and community?

'ET LUX (ALSO, LIGHT)' BY ROBIN M. EAMES

- ◆ Like Eliza Hull, Eames initially used language other than disabled to describe themselves. What does this substitution of language tell the reader about how disability was viewed in the community?
- ◆ How did Eames benefit from connecting their experiences with disabled identity (and community)? What was the impact of lacking those connections in childhood?
- ◆ The way Lucy is spoken about highlights the ways disability is often framed in terms of grief and tragedy. What exactly is challenged about this perception in Eames's retelling?
- ◆ How did personal and social perspectives regarding Lucy impact the way Eames saw themselves through a disability lens?
- ◆ Where does Eames say disability is located? What commentary does this make on our society?
- ◆ What does this text suggest about how disabled people are ostracised?
- ◆ What structural factors ensured Eames's survival? How is this used to commentate on the limitations society places on disabled people?

- ◆ How does juxtaposing their life with Lucy's allow Eames to highlight the flawed way disability is viewed by society?
- ◆ Eames invokes a 'call to action against injustice'. What injustice are they referring to? What does society need to change to bring about disability justice?

'DON'T HAVE A BIRD' BY SANDI PARSONS

- ◆ Parsons details her exchanges with a friend who has cystic fibrosis, and explains how she didn't understand the viewpoint offered by this person. How does Parsons evolve from someone who rejects the narrative to realising the truth of it?
- ◆ Why is it important that the reader is exposed to Parsons' experience as a friend of someone with cystic fibrosis before we see her as someone *with* cystic fibrosis?
- ◆ How does the evolving narrative invite the reader to see how their own perspectives may be ignorant to the depth of experiences a disabled or chronically ill person may undergo?
- ◆ Compare the emotional turmoil displayed in the second half of the text compared to the first. What is it that Parsons wishes to apologise to Julie for? What can the reader learn from this?
- ◆ Parsons realises she was incredibly wrong about Julie and cystic fibrosis. What was her mistake?
- ◆ What does Parsons realise is the cost of survival?
- ◆ What are the two pieces of knowledge that Parsons gained eighteen years too late?

'A BODY'S CIVIL WAR' BY TIM SLADE

- ◆ The poem is formatted in three parts – what information is expressed in each?
- ◆ How is the *italicised* text working with the punctuation (parenthesis, ellipsis, en dash) to present a narrative of the medical perspectives he has dealt with?
- ◆ Who is the enemy in the text? Does the enemy change depending on the perspective taken (Doctor/Slade)?
- ◆ What is Slade showing the reader about the way disabled and chronically ill people are sometimes treated by the medical professionals?

'LUCK AND ANGER' BY TODD WINTHER

- ◆ What privileges did Winther see himself as having while growing up? How does this differ to the world he knew could have been possible?
- ◆ How did his upbringing create an unrealistic moral purpose?
- ◆ What emotional transition does he undergo and why is this important?
- ◆ How does the emotional transition allow Winther to understand the full scope of his disability?

**‘HOW I LEARNT TO STOP WORRYING AND SING
“THE ROBOT SONG”’ BY TOM MIDDLEDITCH**

- ◆ What expectations do disabled and chronically ill people face, and how could these impact their lives?
- ◆ What was Middleditch most anticipating with the performance of ‘Robot Song’?
- ◆ Middleditch has three critical points and details them quite clearly. What is the perspective offered in each of the points and what is the validity of each point?
- ◆ How have Middleditch’s lived experiences formed the basis of his criticisms?
- ◆ What do his criticisms of ‘Robot Song’ tell the reader about his lived experiences?
- ◆ How had he misconstrued ‘Robot Song’?
- ◆ Why was it important for the reader to see Middleditch go through the process of sharing his grievances? What does this process show the reader of Middleditch’s experience?
- ◆ What hurt does Middleditch share with the reader? Explain the lessons that various groups of people can learn from this.
- ◆ What does Middleditch show to be the real ‘othering’ experiences he faced (if not his disability)?
- ◆ Explain the realisation Middleditch has about representation. What sort of representation is important?

‘FREE AS A BIRD’ BY JANE ROSENGRAVE

- ◆ How does the language of the narrative reflect Rosengrave’s unique voice and identity?
- ◆ What does her story reveal about attitudes to disability and Aboriginality? How do these identities converge in this narrative?
- ◆ What is conveyed to the reader about the systemic institutional abuse of disabled people?
- ◆ How is connection to others used as a means of creating belonging and sense of self, *and* as a means of punishing and creating ‘otherness’?
- ◆ What is the juxtaposition the Browns offered to Rosengrave’s life?
- ◆ What is heartbreaking about the way Rosengrave used lamb’s wool as a substitute for physical touch?
- ◆ How does the way in which Rosengrave was informed of her mother’s death speak to the way she had been dehumanised by the institutions?
- ◆ What systems were in place that ensured Rosengrave remained silent about her abusers?
- ◆ What does Rosengrave show the reader about the irony of the institutions’ names?
- ◆ How does the description of her life in the sheltered workshop show how Rosengrave was linked to the outside world, but never able to properly partake in it?
- ◆ How is Rosengrave now able to fully participate in society?

- ◆ How does the motif of the bird evolve throughout the text – from one caged to one free?

‘THE BOY WHO ACHED [FIBROMYALGIA]’ BY MARLA BISHOP

- ◆ Explain the disparity between the perspectives shown in the poem – the boy, the friends and the medical professionals.
- ◆ What issues did Bishop face in the quest for support?
- ◆ How is the reader invited into Bishop’s world and asked to see it from this perspective instead of through the outsider’s lens?

‘RED DUST, JET STREAMS AND CHANEL NO. 5’

BY GAYLE KENNEDY

- ◆ How did Kennedy’s experience of ‘growing up disabled’ shelter her from the world?
- ◆ How did her hospital life disconnect her from her cultural heritage?
- ◆ Describe the social trauma Kennedy experienced when leaving the hospital. Kennedy had to re-learn her place in society. What social factors were at play and how was disability a part of this?
- ◆ Compare the way Kennedy describes the hospital and her home – how is the imagery different, and what does this suggest to the reader?
- ◆ How did people’s expectations affect Kennedy’s perception of her ability to be loved?
- ◆ Kennedy says her ‘*mojo went walkabout*’. What does she mean?
- ◆ What experiences helped Kennedy feel whole again? How does this link to the title of her piece?

‘BORN SPECIAL’ BY KATH DUNCAN

- ◆ Duncan opens her piece with a very clinical description of her birth. What does this say about how her type of birth was seen by medical professionals?
- ◆ What does the reader learn from Duncan’s retelling of her mother’s experiences? Consider her mother’s separation from others, and her mother’s reply to doctors.
- ◆ ‘*I was claimed by the Special sector from the start*’. What are the highs and lows Duncan experiences being in this community?
- ◆ How did the institutions Duncan attended medicalise and ‘other’ her and other children in their care?
- ◆ What phrases does Duncan use to show how the community’s mindset separated her from others?
- ◆ Where did Duncan find connection? How did this occur?
- ◆ What does Duncan expose about the views society often holds about disabled people?
- ◆ ‘*It takes a lot of guts to be born different*.’ What ‘guts’ do people need, and why?

- ◆ How does Duncan challenge the perceptions people have about the value that marginalised people bring to society?
- ◆ How does Duncan challenge the dominant narrative in her life and redefine herself?
- ◆ How does the language Duncan uses challenge society's view of disability?
- ◆ What expectations of behaviour does Duncan shun? How does this mirror her overall realisation about the power of disability?

'NO MIDDLE GROUND' BY YVONNE FEIN

- ◆ *'But a rose by any other name ...'* What is the importance of owning language used about oneself?
- ◆ How does Fein show how *'the other'* is defined?
- ◆ What is the intergenerational legacy linked to disability in Fein's piece?
- ◆ *'I did nothing to deserve bipolar.'* How does the language Fein uses reveal society's view that disability is a punishment?
- ◆ By describing people experiencing Holocaust trauma and mental health issues as 'luckier', how does Fein show disability and chronic illness as indiscriminate?

'A POLIO STORY' BY FRAN HENKE

- ◆ Henke describes her diagnosis of poliomyelitis as *'retribution'*. What does this say about the prevailing belief about illness and disability?
- ◆ Henke's precise explanation of the history of polio highlights the way fear governed a lot of people's actions. How did this link to the perceptions mentioned later in the text, and what can the reader learn from this?
- ◆ What does Henke's explanation of Dr Dame Jean Macnamara's choices reveal about the way Australians often deal with issues? What can the community learn from this?
- ◆ What is shown about the experimental nature of dealing with disability and illness? How can this impact a person?
- ◆ How is doctors' expertise now challenged in a way it wasn't before?
- ◆ What does the reader learn from Henke's description of the growth unit?
- ◆ What insight has Henke's polio experience provided?

'LADY LAZARUS' BY CARLY-JAY METCALFE

- ◆ What is the impact of Metcalfe intertwining Sylvia Plath's poem with her own?
- ◆ What is Metcalfe sharing about her life, and how is this concept overshadowed by death?
- ◆ Is a medicalised life the opposite of death, or a living death? What is Metcalfe's poem suggesting?

‘SURPRISING MYSELF’ BY ISIS HOLT

- ◆ ‘Nothing says, “*I can do this*” quite like crossing a line in first place.’ How does Holt’s story reflect the redeeming qualities Australians often associate with sport?
- ◆ How has sport been an enabling and empowering process in Holt’s life?
- ◆ Why was Holt confused about her disability identity?
- ◆ What was the role of humour in her life?
- ◆ ‘*I loved proving people wrong.*’ What misconceptions did Holt face, and how do these match other peoples’ experiences?
- ◆ What comradery is found in the sports community? What is the benefit of this?

‘THIS IS MY SONG’ BY LUCY CARPENTER

- ◆ The way Carpenter is treated speaks to the overarching mindset about disability. What is this mindset and how does Carpenter’s treatment show this?
- ◆ What does Carpenter’s narrative reflect about the community’s sense of entitlement to the disabled person’s identity? How does their questioning and requests for evidence of disability and chronic illness highlight the lack of respect people have to live with?
- ◆ How did understanding how she was different to others allow Carpenter to modify her behaviour when needed? Refer specifically to the *jam sessions* in the car.

‘CATCHING MEANING’ BY NATALIA WIKANA

- ◆ How did the comments Wikana heard through her life (*italicised font*) affect her self-esteem? What can the reader learn about the way they speak about and around other people?
- ◆ How does the external narrative from the community impact Wikana’s psyche?
- ◆ How does Wikana’s internalised narrative reflect the societal perception of her disability?
- ◆ What is Wikana showing the reader about the damage stereotypes have on people who are expected to adhere to them? What intersecting stereotypes does she feel pressure from?
- ◆ Why does Wikana try to gain acceptance by denying elements of herself? How does this behaviour reflect the struggle many disabled people undergo?
- ◆ How did Wikana’s disability experiences drive her anxiety? What could the reader learn from this?
- ◆ Consider all the negative language Wikana uses to describe herself. Where did this language come from?
- ◆ How does Wikana eventually manage to redirect the words used against her?

‘THE BEDRIDDEN ASTRONAUT’ BY MELANIE REES

- ◆ The subtlety of the use of the past-tense *‘wanted’* is picked up by Melanie as a child. How is this language the first clue of change in her life?
- ◆ What is the impact of being talked about instead of talked to?
- ◆ How does the reference to the movie *Gattaca* show how Rees was feeling about her newfound life?
- ◆ How is Rees disempowered throughout her experience? What could medical professionals learn from her account?
- ◆ What does Rees’s diary entry tell the reader about her emotional turmoil? What has caused this turmoil?
- ◆ How did Rees create a supported reality in which she could thrive?

‘FALLING’ BY K.Z. BARTON

- ◆ Why do you think people felt it acceptable to be *‘discussing [Barton’s] progress from down below’*?
- ◆ How did creating the metaphor of the *‘parachute’* help the non-disabled people to understand the life-giving qualities of Barton’s disability aides?
- ◆ How did Barton come to understand her body by no longer explaining it through non-disabled terminology?
- ◆ What caused Barton to lose faith in the medical profession? What lesson can be taken from this?
- ◆ What does Barton demonstrate about the importance of self-advocacy?
- ◆ How does dismissing the expertise of the lived experience cause problems? How is the seriousness of the problems emphasised?
- ◆ What fight has she *‘waged for so many years’*?

‘UMBRELLAS IN THE RAIN’ BY EMMA DI BERNARDO

- ◆ Who or what causes the *‘perennial grief’* Di Bernardo talks about?
- ◆ How is the concept of *resilience stemming from disability* challenged? What romanticised view of disability and chronic illness is disputed?
- ◆ How does Di Bernardo suggest one deals with the *‘othering’* experienced as a disabled or chronically ill person?
- ◆ How did the doctor, and the medicalised lens with which they viewed Di Bernardo, lead to her being dehumanised?
- ◆ How is the disability Di Bernardo lives with inherently gendered? How can this gendered nature of chronic illness and disability make being heard difficult?
- ◆ What is Di Bernardo saying about the hero narrative that is aligned with disabled people?

‘DRESSING TO SURVIVE’ BY JESS NEWMAN-MARSHALL

- ◆ What physical and emotional changes is the reader asked to experience via the perspective of thirteen-year-old Newman-Marshall?

- ◆ What does the reader learn from Newman-Marshall's depiction and discussion of nakedness? What is this telling the reader about how disability and chronic illness is treated in society?
- ◆ What is shown to the reader about how disability and chronic illness can become dehumanising? Why does this occur? Refer to the perspective offered by fifteen-year-old Newman-Marshall.
- ◆ What does the private school's use of the accessible toilet tell the reader about how disability and chronic illness are viewed in society? What is given priority?
- ◆ Consider the mistreatment Newman-Marshall experiences. What level of gratitude for this treatment is Newman-Marshall expected to show? Why?
- ◆ Connection with people who are the same as you can offer a respite. What burden does this connection also carry?
- ◆ Who flouts *Darwin's laws*? What is important about this act of defiance?
- ◆ Consider the gendered restrictions that come with disability. How do these contribute to disability or chronic illness being perceived as a crime?
- ◆ How is access to fertility an unseen aspect disability? Why is this issue rarely considered when thinking about disabled or chronically ill people?
- ◆ What role does the support from parents play in developing independence (without taking away agency)?
- ◆ Explain the importance of the clothes Newman-Marshall uses to symbolise how she identifies in and with her world.

'IT IS 1975, I AM NEWBORN' BY RICKY BUCHANAN

- ◆ What is the disparity between Buchanan's understanding of her life and other people's perceptions?
- ◆ How is Buchanan disempowered by being a child?
- ◆ The reader first thinks things have changed after Buchanan turns eighteen. How has her treatment as a child repeated as an adult, and what does this tell the reader about society's understanding of invisible illnesses and disability?
- ◆ Why is it so important to be heard by medical professionals?
- ◆ Why is Buchanan considered 'not really "*properly disabled*"'?
- ◆ How has Buchanan been let down by the medical field? What is the long-term impact of this?
- ◆ What is Buchanan showing the reader about the Australian community when she explains why her disabilities and illnesses are listed in the way they have been?
- ◆ Buchanan finishes each section with a statement about how she feels. What does this statement tell the reader about the experiences she details, and the role each experience had in shaping her identity?

**'MY EARLY YEARS (CONDUCTIVE ED PRESCHOOL)'
BY OLIVER MILLS**

- ◆ What is shown to the reader about how people are taught to conform within Australia?

- ◆ What is the significance of the '*legion of helpers*' who move Mills's body?
- ◆ What can the routines Mills experienced as a child tell the reader about Australia's expectation for people to comply with the majority?

'AWAKENINGS' BY TULLY ZIEGER

- ◆ How did Zieger's initial recount highlight her lack of acceptance for her disability? What words or phrases show this?
- ◆ What role did Zieger's mother play in confronting the misguided reality Zieger had created?
- ◆ How did the disability aide (walking frame) lead to greater independence?
- ◆ What paradox does Zieger's '*delusion*' offer? Why might this be so?
- ◆ Why does Trudi's role in Zieger's life form the bulk of the narrative? What changes did Trudi instigate, and why were these so important?
- ◆ '*The two are not mutually exclusive.*' What did Zieger have to come to terms with? Why might she have needed assistance to learn this?

'BLURRED LINES' BY IMAN SHAANU

- ◆ Shaanu's opening line challenges the reader's perception of beauty. Why is beauty seen to be so separate from disability?
- ◆ What further hurdles did Shaanu have to face in her life? How was her disability impacted by cultural norms and misconceptions?
- ◆ How was Shaanu's family further restricted from supporting her? How might this issue affect many people across Australia?
- ◆ What is the cultural impact of disability in a country that already ostracises marginalised groups? How can marginalisation of cultures cause further barriers to disabled people?
- ◆ How did culture and religion ultimately allow access to community and acceptance?
- ◆ How does Shaanu demonstrate a fear of being removed from society for a lack of worth? What does this reveal about the portrayal of disability in Australia?
- ◆ How did the strong ethnic identity pressed upon Shaanu by other Australians restrict her from connecting with her disability?
- ◆ How have ethnicity and disability been balanced? Where are the lines blurred?

'LEARNING MY PLACE' BY CHANTEL BONGIOVANNI

- ◆ How does Bongiovanni highlight the problem of the non-lived experience becoming the prevailing narrative?
- ◆ What '*isn't meant*' for disabled people? What belief is challenged by Bongiovanni's narrative?
- ◆ How do the low expectations shown in this narrative highlight the way barriers are imposed on disabled and chronically ill people by others?

- ◆ What is shown about the pervasiveness of systemic low expectations which have taken hold?
- ◆ Why does Bongiovanni find it especially galling that Mr Robins had these low expectations?
- ◆ What is Bongiovanni's 'place'? How does this differ to what she was taught was her place?

'MOTHERHAND' BY JASMINE SHIRREFS

- ◆ How does the pace of the narrative reflect the language in Shirrefs' life? What is the significance of calling this language the '*Mother hand*' instead of the '*Mother tongue*'?
- ◆ What does the reader learn about the slightly disconnected nature of Shirrefs' life?
- ◆ What is the '*intensity and permanency*' of Shirrefs' life caused by?
- ◆ What is important about the reader being required to translate the pace of the language in order to understand the way Shirrefs has had to translate her life?
- ◆ What barriers does Shirrefs continue to face?

'AMATEUR LINGUISTICS' BY LAUREN POOLE

- ◆ What is revealed to be the power of words and language?
- ◆ How does Poole show an evolution of language that has been used to separate disabled and chronically ill people from their community?
- ◆ How has she used language to make sense of her change in circumstances?
- ◆ How is the meaning offered by particular language subverted when attached to disability? Why does Poole point this out?
- ◆ What is shown about the desire to use language and euphemisms to hide the truth? How does this contribute to systemic othering?
- ◆ How did euphemisms reduce the truth and suggest there could be shame in truth? Why is there no shame in truth?
- ◆ How is mental health rephrased to show its long-lasting impact and presence? Why is this important?
- ◆ How does Poole suggest that society needs to accept disability and see it as a part of a whole? What role does language play in this process?

'E IS FOR EARWAX' BY KHANH NGUYEN

- ◆ What is the significance of the selected letters?
- ◆ What does the visit to the magical baby illustrate about the way disability and chronic illness is perceived?
- ◆ What does the reader learn about the emotional impact of a progressive degenerative illness?
- ◆ Why has Nguyen given up grief? Why does he link this loss to a 'trade' with the 'devil'?

- ◆ How do gender expectations impact the way emotions linked to progressive disability and illness are processed? Why would Nguyen have thought this was important to show?
- ◆ What frustration is caused by his mother's insistence to make *chao*? What does this exchange highlight about the loss of agency and voice?
- ◆ Why does Nguyen feel the need to justify that he has seen the parent point of view? What does the reader learn about Nguyen's acceptance of not being heard?
- ◆ How did the last line in his narrative show he has been seen and heard?

'DRAWING MY WAY' BY SARAH FIRTH

- ◆ How does Firth use symbols to present the world she experiences? Describe the way each cell represents the world she lived in.
- ◆ How do the graphics represent Firth's perspective and not other people's? Why is this crucial?
- ◆ How does the shading and use of graphic weight in the aeroplane scene convey Firth's inner thoughts?
- ◆ How does Firth's use of sound and movement symbols represent her life and how it is perceived by others?
- ◆ What does the classroom cliff picture represent about how Firth has experienced her life?
- ◆ What role did her mother play in creating acceptance and ensuring Firth had access to the world?
- ◆ What is shown about the continued shame and judgement Firth experiences in her life? Why is it important to see how this treatment has lingered?
- ◆ How did the fear of being medicalised and labelled restrict Firth's access to the world?
- ◆ How did she give herself permission to be open, and in turn reduce the shame she felt?

'WHO COUNTS AS DISABLED ANYWAY?' BY ASTRID EDWARDS

- ◆ The reader is first introduced to Edwards' experiences before they are told why she doesn't seek help. How does this highlight the fears Edwards has, and what systemic issues have fuelled these fears?
- ◆ What is the privilege and problem with not looking sick?
- ◆ How does the invisibility of Edwards' illness contrast with the very detailed description of its impact? What can the reader learn about this?
- ◆ How has the invisibility of Edwards' illness affected her ability to identify as being disabled?
- ◆ What barriers does Edwards perceive are created by the continued silence of famous chronically ill people with regards to their conditions?
- ◆ Why does Edwards feel like a stranger in her own body?

- ◆ Her last question – ‘*Do I belong in this anthology?*’ – is an indication of the narrative she has heard in life. How did this narrative cause Edwards to question her place in the disabled and chronically ill community? Whose criteria is she asking to be confirmed or denied?

‘CURVE’ BY JESSICA WALTON

- ◆ ‘*But I’ve done it wrong.*’ Whose rules have dictated that Walton’s actions are incorrect?
- ◆ What did Walton find out about society after she recovered from cancer?
- ◆ How does the attitude and approach of the two different prosthetists affect Walton’s life as a disabled person?
- ◆ Walton says, ‘I’m practising being proud, like Laura told me.’ This is reference to a poem by Laura Hershey about disability pride, ‘You Get Proud By Practicing’ (www.thenthdegree.com/proudpoem.asp). What is the importance of disability pride to Walton, and why would she need to practise being proud?
- ◆ How is Walton’s dream taunting her? Why does she depict this happening to her?
- ◆ What is the importance of being able to tell your story and have it validated?

PART D

Learning activities

AFTER READING, THE FOLLOWING THEMES CAN BE FURTHER EXPLORED:

Identity and ownership of narrative voice

Many of the authors have had an identity imposed upon them by others. The society they have lived in has a preconceived notion of disability and chronic illness, and this perception guides how people with disabilities and chronic illness are treated.

Many people who have grown up disabled and/or chronically ill have relied on parental advocacy in the early parts of their lives. This has resulted in the advocate’s voice being the prevailing experience understood and retold in society. Many of the authors in the anthology show the struggle to be heard, and to be seen as an individual.

Voice and ownership of the disabled story

Privacy is an increasing concern in a world where social media and online publications are now prevalent. Many disabled and chronically ill people have felt a lack of privacy, agency and ownership in their lived experience.

In the past, shared stories about disability and chronic illness have often been from the parental or medicalised perspective. These perspectives have centred on the way the disability or chronic illness has affected the carer, how the disability or illness can be managed or eradicated from our society, or the issues the disability or chronic illness causes society as a whole. There has also been an underlying idea that disability and/or chronic illness is a punishment, and is something that people should strive to ‘overcome’ by following rules or ‘being good’. Instead, the authors in *Growing Up Disabled in Australia* show the power offered by disability and/or chronic illness, and highlight the way the disabled story has been distorted – incorrectly showing them as ‘weak’ or lacking in worth. *Growing Up Disabled in Australia* shifts the perspective to the way disabled and chronically ill people experience the world, and the affect the parental and/or medicalised lens has on them. Many of the authors have experienced a struggle for bodily autonomy in a world where permission wasn’t always seen as a right for all groups in our society.

Converging and intersecting identities

The way disability and chronic illness have been portrayed has meant that often the disability or chronic illness is the dominant aspect of a person’s life that is acknowledged or recognised. However, there can be myriad limiting factors in a person’s life, including being a part of other marginalised groups.

The anthology shows people being treated in certain ways due to disability and/or chronic illness, as well as the added restrictions they may have experienced due to other aspects of their identity or life, such as poverty, racism, gender-specific treatments or expectations, and sexuality.

Disability and chronic illness is not cisgender or heteronormative, but alternatives to this view are not always recognised. Disability and chronic illness also affect the experiences a person has of gender and sexuality.

Evolving social conscious

There is a clear focus on the social model of disability, a shift from the previously held medical model of disability. While this shift has meant a change in the way disabled and chronically ill people are institutionalised or shunned from society, disabled people still experience considerable ableism in the community.

Many of the authors describe the impact that institutions or medicalisation has had on their lives, and the way the previously held views have resulted in restricted access to society. As the lens through which disability and chronic illness is viewed is moved from the carer’s to the individual’s lived experience, the community is becoming more aware of how the previous model has negatively affected people. The community increasingly recognises that not all disabilities and chronic illnesses are obvious, and all people have the right to privacy and agency.

The evolving social consciousness is reflected in the recent demand for a Royal Commission into the systemic abuse of disabled people in care.

Defying systemic low expectations

Many of the authors highlight the way the community sees disability and/or chronic illness as a deficit. The flow-on effect of this is that many people – consciously or unconsciously – see disabled or chronically ill people as a means of creating a hero narrative for the carer or medical professional. This narrative relies on viewing the disabled or chronically ill person as helpless, and implies the carer or medical professional is the more worthy. *Growing Up Disabled in Australia* highlights the long-term impact that low expectations have on people with disabilities or chronic illnesses, and shows these to be more limiting than the disability or illness itself.

Impact of the othering narrative

The *othering* narrative is at play when disabled or chronically ill people are deliberately excluded from society via:

- ◆ restricted physical access, or restrictions to offering opinions or gaining knowledge
- ◆ deliberate focus on the deficits the disability or chronic illness presents
- ◆ language that reduces the person's standing or perceived capacity in society.

This results in marginalisation and a perceived reduction in worth to society. It also results in people with disabilities or chronic illnesses being seen as a burden that others need to cope with.

This anthology allows access to the inner thoughts of disabled and/or chronically ill people and emphasises the way the prevailing narrative has separated them from, or reduced their access to, society.

The lasting impact of this narrative has been the dehumanising of whole groups of people.

Language

Language is used to elevate certain groups and or marginalise others. It has been used to separate, vilify and remove the autonomy of disabled and chronically ill people.

The language used to describe people often becomes the internalised narrative of these groups, and when this is done in an adversarial manner it can cause long-term damage and trauma.

This anthology shows the impact that limiting or pejorative language has on the self-esteem and self-efficacy of people with disability or chronic illness, and the manner with which this language is being reclaimed to reject previously held notions. Some authors also show the violent nature of the language used against disabled or chronically ill people, or the way euphemisms remove elements of identity that make up a significant part of the whole individual.

There has also been language and phrases coined by the disabled and chronically ill community, which highlights how the language available did not adequately represent the lived experience.

EXTENDED RESPONSE TO TEXT

Students may be asked to respond analytically to the work in *Growing Up Disabled in Australia*. Here are some possible essay questions.

1. Steele-Johns says that he gained a 'prize' for 'liberating [him]self from the illusion of not being defined as a disabled person'. How does *Growing Up Disabled in Australia* suggest that people draw strength from being part of a community?
2. *Growing Up Disabled in Australia* highlights the way language can either empower or demean a person. Discuss.
3. *Growing Up Disabled in Australia* challenges the prevailing narrative held about disability and chronic illness. To what extent do you agree?
4. How has *Growing Up Disabled in Australia* exposed the depth of restriction that disabled and/or chronically ill people face in society?
5. How does *Growing Up Disabled in Australia* show how language is used to restrict people?
6. The editor, Carly Findlay, has selected texts that reflect a range of ways disability and chronic illness is viewed by Australians. How does the selection challenge the perceptions held by many people in our community?
7. Despite the vastly different experiences reflected in the stories, the overall message is one of defying expectation. To what extent do you agree?
8. Being in control of the way your story is told can lead to greater levels of learning for others. To what extent does *Growing Up Disabled in Australia* invite the reader to see the world through a new lens?
9. How does the text reflect a strong desire to shift from a medicalised model of disability to a social model of disability?
10. *Growing Up Disabled in Australia* holds a mirror up to Australian society, and reflects a changing landscape. Do you agree?
11. Many of the authors see themselves as having 'survived' childhood. Findlay's selection condemns the way in which society has created an adversarial experience for disabled and chronically ill people. Discuss.
12. How does the language used by the authors reflect the vast diversity in disability and/or chronic illness?

13. *Growing Up Disabled in Australia* highlights that the difficulties faced by disabled and chronically ill people are multifaceted. How does the anthology create a common thread for the reader?
14. How is language repurposed and reclaimed in the anthology to better reflect the experiences of disabled and chronically ill people?
15. To what extent does *Growing Up Disabled in Australia* make the invisible lives of people with disabilities and chronic illnesses visible?
16. At times, the authors in the anthology speak to a younger version of themselves with a particular message that they hope readers will also heed. Is this a text for disabled and chronically ill people or society as a whole?
17. *Growing Up Disabled in Australia* places control of the narrative with the disabled and/or chronically ill person. How has the editor shown the importance of listening to the lived experience?

Teaching Notes by Christine Davey-White

Christine Davey-White is the English and Literacy Leader at Cranbourne East Secondary College. She has worked in a number of government secondary colleges in Victoria, and has led teachers in the development of curriculum, improving instructional practice, and improving literacy across curriculum areas.