

Stories in Chronic Illness and Disability

Reflection
Inquiry
Action

Esther Chang
Amanda Johnson



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**Stories in Chronic Illness and
Disability:
Reflection, Inquiry, Action**

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Stories in Chronic Illness and Disability: Reflection, Inquiry, Action

Edited by Esther Chang and Amanda Johnson



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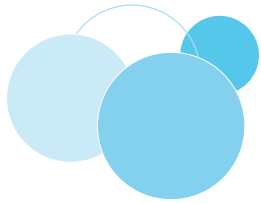
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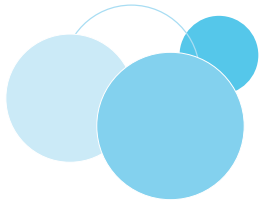
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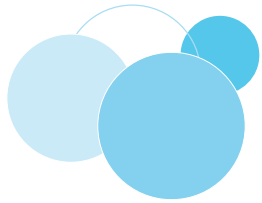
Professor Esther Chang is an Emeritus Professor at the Western Sydney University. She is a Registered Nurse and a Midwife. She has worked in academia since 1986 with three tertiary institutions. She has held roles as a Clinical Nurse Educator, Head of School, Dean of the Faculty of Health, Acting Pro Vice-Chancellor Academic, Director of International and Business, Director of Research and Director of Higher Degree Research. Professor Chang's research for over 25 years has been in aged care, with an emphasis on models of care for people with dementia and palliation. She has co-edited over 20 books to assist students in tertiary institutions, new registered nurses, and clinicians to improve health care and provide guidance for future generations of nurses and midwives.



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Professor Amanda Johnson is a Professor of Nursing at the University of Newcastle where she holds the role of Head of School, Dean of Nursing and Midwifery and Campus Lead for the Central Coast Clinical School. She is a Registered Nurse, having worked in academia since 1992 with three tertiary institutions holding senior management positions. Professor Johnson has been the recipient of a Vice Chancellors Excellence in Teaching Award (Highly Commended) for her work in chronic illness and disability having established the subject and co-edited a textbook, now in its 4th edition to support student's learning and the delivery of optimal care. Professor Johnson has a commitment to excellence in care for vulnerable people and continues to research in aged care and palliation using this knowledge to inform undergraduate nursing curricula and professional placement experiences culminating in the preparation of graduates for future practice.





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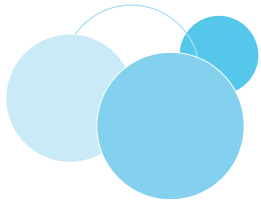
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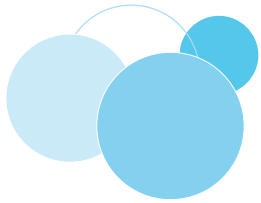
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Aaron

Jamie

Grant

Bonnie

Jacqueline

Rebecca

Peter

Clare

Holly

Karen

Nell

Bronwen

Melissa

Eleanor

Zoe

Karen

Lois

Nicholas

Sharon

Heather

Dave

Carla

Sarah

Thida

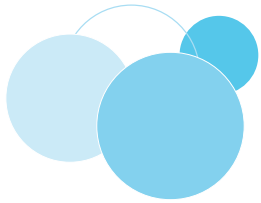
Rebecca

Ruth

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About this resource

Overview

This resource has been developed for tertiary nursing students, students in the TAFE sector, newly registered nurses and other health professionals who share our commitment to providing quality of care to people living with chronic illness and disability.

This resource is also based on the stories of people living with chronic illness and disability. It discusses the issues and challenges for health professionals and carers providing quality of care to people living with chronic illness and disability.

The aim of this book is to give students a better understanding of the lived experiences of people with chronic illness and disability. Learners will find viewpoints that are challenging and sometimes disconcerting, but at the same time motivating and thought provoking. Research has shed much light on the issues associated with chronic illness and disability, and has uncovered knowledge, including strategies that can be useful in negotiating the process of partnership with empathy.

Using the resource

Our intention was to involve clinicians, academics and people with chronic illness and disability and their carers, in producing a resource that is scholarly, accessible, reality-based and practical.

By reading the book, watching the videos, critically reflecting on the issues and posing possible answers, learners will be able to gain a comprehensive view of the issues, challenges and opportunities that lie ahead for them.

This resource can be also used as a tool for teaching and learning, critical reflection, inquiry and action, guiding the teacher and student through each chapter and at the same time allowing the learner to examine their beliefs and assumptions that have influenced their practice.

Research articles and chapters in books have also been selected for your reading and consideration as you progress through this comprehensive resource book. Each section has been provided to enable you to reflect on what you have learned in relation to people with health needs by reviewing the Registered Nurse Standards: <https://www.nursingmidwiferyboard.gov.au>

Structure of the resource

There are several constructs, key elements and questions that have guided authors within each chapter.

The stories

Storytelling brings lived experiences to life and helps the learner to remember key facts, as stories are easy to remember. Organisational psychologist Peg Neuhauser (1993) found that learners remembered more accurately and for far longer by storytelling. She believes that telling stories is one of the most powerful means that leaders and, in this case, teachers can influence, teach, inspire and motivate their learners.

Telling stories forges connections among people by bringing in history, culture and values that unite people and, in this case, your patients or clients, their families, or carers. It also allows you to have a better understanding of the needs and person-centred care for the individual.

About this resource

Stories also promote time for personal reflection for the student to consider their own stories. Reflective practice is included as a component of the activities within each chapter, as it is an essential part of the learning process.

Each chapter focuses on a specific key understanding which is identified within the chapter heading. Within each chapter are several headings including Reflection, Inquiry and Action, with references and further reading lists at the end of the book.

Reflection

The learner is asked to think about what they have listened to and make some personal judgement on this information. There are several questions that will help with this process and guide key learnings. This section is useful for learners at all levels.

Inquiry

This section has been written to help the learner consider what else they need to know as well as identify any gaps in the knowledge presented that needs to be considered, along with potential solutions.

Action

This is divided into three questions: 1, 2 and 3.

Within this section, the learner is invited to apply their knowledge and understanding to not only their personal practice but also to the organisational and political frameworks in which their practice is embedded.

This section has been organised within a stepping-up framework:

1. Generally, asks the learner to apply their knowledge within the boundaries of their own personal practice.
2. Starts to introduce the notions of action within an organisational structure.
3. Generally, asks for the knowledge gained to be applied within the greater political framework.

It should be noted that it:

1. will be better focused for the certificate level learner
2. will be more for the undergraduate learner
3. is intended to stimulate inquiry for the postgraduate learner.

This provides all learners with the opportunity to consolidate their foundational understandings of the data presented before moving on to the more complex concepts identified at the next level. Learners can advance to the next area if they wish and consider the learnings from these notions.

Further reading

Mather, C., & Almond, H. C. (2024). Critically reflective practice for the graduate. In E. Chang, & D. Hatcher (Eds.), *Transitions in nursing: Preparing for professional practice* (6th ed.). Elsevier.

Neuhauser, P. C. (1993). *Corporate legends and lore: The power of storytelling as a management tool*. McGraw-Hill.

Rolfe, G., & Freshwater, D. (2020). *Critical reflection in practice: Generating knowledge for care*. Bloomsbury Publishing.

White, J. (2024). Becoming a competent, confident, professional registered nurse. In E. Chang, & D. Hatcher (Eds.), *Transitions in nursing: Preparing for professional practice* (6th ed.). Elsevier.

CHAPTER 2

Living with a person with disability

Nathan J. Wilson



INTRODUCTION

This chapter will present short stories about three men who are living with a disability and disability-associated chronic illnesses. By engaging with these stories and the reflective activities in this chapter, the reader will become more acquainted with some of the issues facing people with a disability and will be better equipped to be a more responsive and adaptable health practitioner. Key issues are centred around activity and participation limitations due to disability, the intersection of chronic illness and disability, and a strong desire to achieve personal goals despite the daily challenges these men face. But first, a short introduction to the three men who have shared their stories.

Before you begin

Key contextual issues

- **The International Classification of Functioning, Disability and Health (ICF):** Central to the lives of all people with disabilities, including that of Aaron, Jamie and Grant, are the activity limitations, participation restrictions and intersecting health problems that result from having a physical disability. The ICF is a (2001) World Health Organization-endorsed framework for measuring both health and disability, and all health and social care workers should know about the framework as it helps to contextualise the often

all-encompassing impact of having a disability. That is, a person's disability does not exist solely as an impairment to body function or structures – such as having a spinal cord injury resulting in quadriplegia – rather it is a dynamic interaction between health, personal and environmental factors, as illustrated in Figure 2.1 below. Importantly, the environmental factors are the barriers or facilitators that enable a person to live independently in society.

- Before reading on, think about someone you know with a disability and use the ICF model illustrated in Figure 2.1 to get a detailed insight into the dynamic factors that are at play that disable the person. In particular, think about

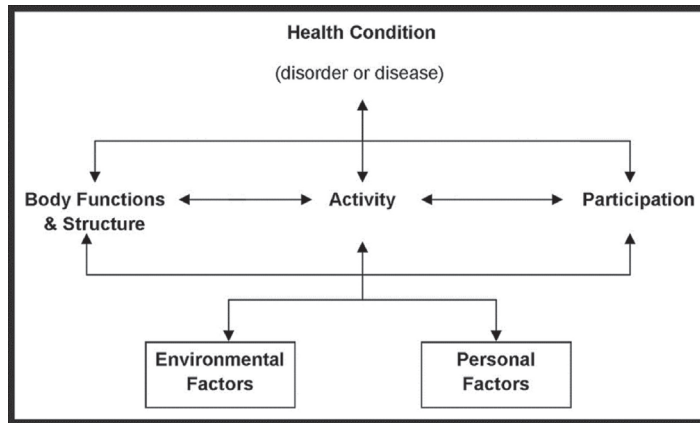


Figure 2.1 The ICF. (Source: *Reproduced from Towards a Common Language for Functioning, Disability and Health: ICF, The International Classification of Functioning, Disability and Health, Page No.9, 2002, WHO.*)

the environmental barriers and facilitators specific to this person. For example, if the person you are thinking about uses a wheelchair, what modifications can you identify – such as wheelchair ramps or accessible public transport – that promote their participation in society? Once you have listed these facilitators or barriers, think about what restrictions this would place on their activity or participation if they did not exist.

- Terminology:** There are many terminology nuances within the disability field that are worth knowing as they are directly relevant to the holistic care and support that a person with a disability receives from health and social care workers. One main difference is between a lifelong and an acquired disability. For instance, Grant has an acquired disability as, prior to his spinal cord injury, he did not live with a disability at all and so most of his life experience was as a non-disabled person. Aaron and Jamie, on the other hand, have a global developmental disability as their disability occurred at birth and so has directly affected all of their developmental milestones. So, all three men have a physical disability, however Jamie and Aaron have always had a disability and, in addition, have a mild intellectual disability that is associated with their cerebral palsy. Note, however, that not all people with cerebral palsy have an intellectual disability, although they often co-occur (Wilson & Charnock, 2022).

- Knowledge and attitudes of health workers:** The third, and final, vital contextual issue that you should consider relates to the knowledge and attitudes of others towards people with disabilities. Of note is that some of the main healthcare barriers and health disparities faced by people with disabilities are the knowledge gaps and sometimes negative attitudes of health and social care workers towards them. With respect to knowledge gaps and nurses, a recent literature review about registered nurses' perceptions of caring for someone with intellectual and developmental disability showed that they felt underprepared, faced communication barriers and were unsure about the role of family and/or paid carers (Lewis et al., 2017). This is important as feeling confident and competent to provide nursing care to an individual, regardless of any individual requirements, is vital for everyone. Notably, a very recent Australian survey of registered nurses showed that most had never received any education specific to people with intellectual and developmental disabilities and very few had been on a clinical placement during their education (Cashin et al., 2021). These knowledge gaps contribute to poor healthcare experiences by people with disabilities and are also associated with poor attitudes. For example, an integrative review by Desroches (2020) reported mainly negative attitudes by mainstream nurses, with limited knowledge and experience key factors.



Aaron's story



View Aaron's story or read his transcript.

Aaron is a man in his mid-thirties who lives in a supported accommodation facility with four other people with a disability. Aaron is a keen sports fan, in particular rugby league, and attends a day program two days a week where he participates in a range of life skills and social activities. Diagnosed with cerebral palsy at birth, Aaron also has a shunt for hydrocephalus which requires regular monitoring to assess for signs of a potentially fatal blockage. Aaron has a long-term goal to be an elite sports coach and has started on this journey by completing an online coaching course.

Aaron's story is filled with positivity that is grounded in the reality that life for Aaron is a 'big challenge'. Of note was Aaron's acute awareness of his shunt and the need for regular reviews to avoid the shunt blocking, as it did so often when he was a baby. Hydrocephalus is when the cerebrospinal fluid accumulates within the brain, putting pressure on the skull, and was first noted by Hippocrates in the 5th century BC (Aschoff et al., 1999). The shunt helps to drain the fluid away from the brain, usually into the abdominal cavity, to reduce the intracranial pressure. Aaron also talked about being teased when he was at school, but he managed to cope with this by blocking it out. Having set himself the goal of being an 'NRL Coach', and noting that it was an ambitious goal, Aaron had undertaken an online coaching course. What stands out is that despite a clear interest and the realisation of the many barriers he faced, Aaron did not have a job of any sort and attended a disability-specific day program two days a week where the focus was not about transitioning to work, that the services offered to Aaron were

limiting when compared with his ambitions. Also, that Aaron, a seemingly articulate man with a lot to offer, did not talk about having had a paid job before in his life.

Reflection

1. Would you say that Aaron has reached his potential in life? If not, what might be missing for him and how might he be supported to realise this, and by whom?
2. What impact do you think Aaron's healthcare experiences as a child influence his approach towards his healthcare needs today?
3. Aaron stated that he coped with being teased when he was younger, however this was at a time when inclusive education was in its infancy. Do you think that school children with disabilities in today's inclusive settings experience teasing and bullying? If so, how might that impact their overall health and wellbeing?
4. In your opinion, what might the role of a nurse who specialises in working with people with intellectual and developmental disability play in Aaron's life to help him achieve his goals?

Inquiry

1. The Professional Association of Nurses in Developmental Disability Australia (PANDDA) Inc. is the only Australian professional association for nurses that specialise in the area of intellectual and developmental disability. PANDDA recently revised its practice standards which offer a detailed insight into the biopsychosocial role of nurses, and how they work with individuals and their families in an individualised and person-centred way. Read these standards when you reflect on the above questions, as they will help you to conceptualise the broad scope of practice of these specialised nurses. They can be accessed at this website: www.pandda.net
2. There are mixed reports about the prevalence of bullying people with a disability, but the evidence is clear that bullying can have a significant impact on the person. Read this interesting article, 'Bullying adolescents with intellectual disability' (Christensen et al., 2012), which refers to people with a disability being bullied and bullying others. In particular,

take note of one of the opening background points that bullying has not been widely studied in people with intellectual disability.

Action

1. If you were working with Aaron, what might be the next steps that you could do in order to support Aaron to increase his activity and participation in sports coaching?
2. Once you have decided upon a step that you can take, what members of the multidisciplinary team would you engage with to support Aaron to participate more fully and independently in some form of sports coaching?
3. How do individual funding models work and how might they be used to support Aaron to get more involved in sports coaching?



Jamie's story



View Jamie's story or read his transcript.

Jamie is in his mid-fifties and lives in the same supported accommodation facility as Aaron. Jamie attends the gym once a week where he focuses on muscle strengthening and flexibility as a therapy for his cerebral palsy. Jamie also attends a day program two days a week which is focused on life skills. Jamie has a desire to find a partner and to have children. In addition, Jamie is interested in getting a 'proper' job as he wants to work. In addition to having some underlying mental health issues, Jamie also lives with gastro-intestinal problems that are associated with having cerebral palsy.

Jamie's story covers a number of topics, but his desire for a job and a partner stand out as unfulfilled life aspirations. In Australia there are two main types

of employment for people with disabilities: 1) an Australian Disability Enterprise (ADE), previously referred to as sheltered employment, such as a factory; and 2) open employment, whether supported or independent, in the mainstream employment market. Jamie also talked about his exercises at the gym, where he is supported to work on his muscles, in particular to improve their tone. Although Jamie mentioned that he wanted to walk, it is not possible from his story to know if this is possible or whether the gym exercises were to maintain his current level of function to avoid deterioration as he ages. Such exercise and mobility are crucially important for people who use a wheelchair, as sedentary activity has an impact on many body systems, most notably the gastrointestinal system, where movement through daily activity and mobility is one part of the bowel's way of functioning in a healthy manner. For many people with a disability, however, gyms have many environmental and social barriers, such as the many unwritten social rules at the gym that are particularly challenging for people with intellectual disability. A recently published Delphi study that sought to identify the essential elements of an accessible fitness centre indicated that environmental adaptations and individualised preparations for exercises were important, along with responses to emergencies (Hong et al., 2022).

Reflection

1. Now in his mid-50s, do you think that Jamie might have outgrown a disability day program that focuses on life skills and recreation?
2. What is your judgement about the employment prospects for Jamie, in terms of both type (ADE or open employment) and tasks?
3. What would be the most significant barriers for Jamie to get a job in either an ADE or the open employment market?
4. What are the main health and wellbeing benefits to being in some form of employment?

Inquiry

1. There are many published examples of how to make information or environments more accessible to people with disabilities. Excellent examples of how to make health information more accessible can be found in the Books Beyond Words series, where topics include going to the hospital and preparing for

testicular screening. Here is the link to the website where you can find more information: booksbeyondwords.co.uk

2. The Council for Intellectual Disability also provides some guidelines on how to make environments more accessible. Here is a link to its guidelines for making gyms more accessible: <https://cid.org.au/our-stories/accessible-gyms-and-how-to-enjoy-them/>
3. Have a read of the article 'An evaluation of employment outcomes achieved by transition to work service providers in Sydney, Australia' (Xu & Stancliffe, 2019), which explores outcomes from a transition-to-work program for young adults with disabilities leaving high school in the state of New South Wales. Note the differences between the outcomes based on the size of the service and the implied expertise of the service.

Action

1. If you were working with Jamie, what might be the next steps that you could do in order to support Jamie to identify some opportunities towards his goal of participating in employment?
2. Thinking over these opportunities, what members of the multidisciplinary team would you engage with to increase the chance of Jamie's goals being realised?
3. How do individual employment funding models work in your region, and how might they be used to support Jamie?



Grant's story



View Grant's story or read his transcript.

Grant is a man who sustained a spinal cord injury some six years ago after a fall at his home in a regional area. Grant now lives in a major city in a supported accommodation facility. At one stage only being able to move one of his great toes after his injury, Grant is now able to walk a few steps with support. Although Grant has a very positive outlook on life, he does miss his old social networks and being able to tinker with his cars. Grant has ongoing problems with bladder infections where he accesses weekly care from a registered nurse to prevent hospitalisations for acute exacerbations of chronic bladder infections.

Grant's story is somewhat different to that of Aaron and Jamie's as his physical disability was quite recently acquired in adulthood. This means that most of Grant's life has been as a non-disabled person where the barriers to activity and participation are either absent or comparatively minor. The most important health issue facing Grant was recurrent bladder infections, where despite weekly visits by a community nurse to conduct bladder washouts, he estimated he was still hospitalised for acute infections two to three times per year. Hunter and colleagues (2013) conducted a literature review exploring long-term bladder drainage and noted that although there were many studies reporting clinical urology outcomes, few studies focused on the lived experiences of bladder drainage, such as daily management, satisfaction, stoma and skin care or quality of life. Certainly, for Grant, spending time in hospital each year would have a major impact on his health-related quality of life. A stand-out issue for Grant was his loss of independence and although not being able to swipe away a mosquito on your head would be extremely frustrating, perhaps the biggest impact was social isolation and the loss of friends. Although Grant did talk about befriending the neighbours, he also mentioned attending a disability-specific social group where he went on occasional outings.

Reflection

1. Is Grant's current social life, as described by him, as good as it might get or are there other ways that Grant might be supported to broaden his social networks?
2. What impact might a wider and more dynamic social life have on Grant's wellbeing, in particular his sense of loneliness, depression and isolation?
3. What are the main barriers that Grant faces if he wants to expand his social network and participate in activities outside the disability-specific services he currently accesses?

Inquiry

1. Men's Sheds are an Australian-inspired social space where mainly older retired men get together to socialise as they work on a range of practical projects such as woodwork or metalwork (Wilson & Cordier, 2013). A number of recent Australian studies have explored how men with disabilities have been supported to access Men's Sheds, thus widening their social networks and benefiting from greater activity and participation in terms of both their physical and their mental health. Read the following articles to gain a deeper understanding of how people with disabilities can be supported to participate in mainstream, rather than disability-specific, social groups: 'Men's Sheds: Enabling environments for Australian men living with long-term disabilities' (Hansji et al., 2015); 'A case study about the supported participation of older men with lifelong disabilities at Australian community-based

Men's Sheds' (Wilson et al., 2015); 'Men with disabilities: A cross sectional survey of health promotion, social inclusion and participation at community Men's Sheds' (Wilson et al., 2016).

Action

1. If you were working with Grant, what might be the next steps that you could do in order to support Grant to identify some opportunities, such as Men's Sheds, in his community, to broaden his social network and engage in meaningful participation?
2. If you were to support Grant to attend a local Men's Shed, what members of the multidisciplinary team would you engage with, and why, to make this a success?
3. How do individual social inclusion funding models work in your region, and how might they be used to support Grant to attend a Men's Shed?

A FINAL WORD

This chapter has focused on the stories of three men, and taken the reader on a journey that is centred in the interaction between impairment, activity and participation, in order to illustrate how health and wellbeing outcomes are far more than just being physically healthy. All three men described having a good life, but noted areas of their life that could be improved with the right kind of support at the right time. The ICF framework has been introduced and all health and social care workers should be aware of this dynamic framework and how the experience of disability extends well beyond an individual's diagnosis or impairment.