

The changing nature of educational support for students with disability

Shalene Werth, USQ

Shaunaugh Brady, USQ

Abstract

This paper looks at the past experiences of students with disability at a regional university and examines the changing ways of providing support which better prepare students for entry to the workforce. Previously, the provision of support consisted of advocacy services and other forms of support such as note-taking assistance. Staff in the Disability Resources section identified additional areas that students need assistance with, in order to begin their transition to workforce while they are at university. This developmental approach extends the support available to include assistance with the development of self-advocacy and resilience skills as well as the multi-disciplinary care of self. This chapter examines the specifically designed support delivered via a coaching process outside the expected advocacy roles traditionally undertaken by Disability Resources.

Introduction

Adaption to a higher educational environment is an experience with which students with disability may require assistance. The transition from University to the workforce may also be difficult for these students (Gillies, 2012). Traditionally, the supports available for students with disabilities have consisted mainly of physical adaptations. Students with obvious disabilities, such as paraplegia or visual impairment, were amongst those who were first granted assistance and understanding of disability in the university environment. The learning environment within universities today has evolved to accommodate a varying range of visible and invisible disabilities (Werth, 2012). The responsibility for facilitating such an inclusive setting falls to student services departments, whose staff negotiate accommodations and implement legal obligations within the university. The range of disabilities which students arrive with now require a variety of responses which include changes to assessment, note taking in lectures and the necessary advocacy to achieve these. While vital, these more common forms of support leave a gap in relation to the transition of students from a support framework to one of self-support, especially within a work environment.

This chapter examined the responses of student with a disability regarding the supports available, and then reflects on the developments in support that have been made to assist students with their transition to the workplace. The support framework that the University Disability Resources Section has implemented since 2010 provides the normally expected advocacy and support services. In addition to these, a modified support program has been implemented, which offers students with disability a coach or mentor who assists with training in, and support for, self-advocacy, resilience building and a multidisciplinary approach to their self-care. This form of support has enabled the Disability Resources Section to extend beyond traditional advocacy role and ensure students are well prepared for the workforce through personal coaching/mentoring. Coaching has a very specific role for those with disability. Instead of primarily giving advice and guidance (as mentors do), coaches are more likely to listen and ask questions to help clients [or students] gain awareness (McGonagle & Beatty 2011, p. 13). Mentoring relationships are less formal than coaching relationships... mentors are often in the same organisation as the mentee (McGonagle & Beatty 2011, p. 13). Within this chapter the assistance provided to students cuts across both of these roles. This chapter discusses the features of this developmental model and explores its alignment with the personal layers of management concept.

Background

Theories associated with disability are often associated with different forms of disability. The application of theory is also dependent on the social structures in which individuals with disability function. Tertiary education provides a unique social setting in which people with disability function (Gillies, 2012). People with some degree of intellectual disability may be able to study given appropriate support. These same individuals, when entering the workforce may struggle to gain access to the most basic positions. The situation that students with disability find themselves in is quite unique. Gillies (2012) reports that graduates with disabilities tend to be under employed and under deployed.

Disability Resources have always provided advocacy and organised the various types of supports, such as note takers. Advocacy is defined by the National Disability Advocacy Program as “speaking, acting or writing with minimal conflict of interest on behalf of the interests of a disadvantaged person or group, in order to promote, protect and defend the welfare of and justice for either the person or group” (FaHCSIA, 2012). On its own, this definition does not explicitly address the wider issues of self-advocacy, resilience building

and self-care. Self-advocacy is addressed in the disability literature, however, it mostly refers to intellectual or learning disabilities. It has been argued that the “values, principles and practices of self-advocacy have applicability for all people with disabilities” (Women with Disabilities Australia, 2008, p. 2):

Women with Disabilities Australia (WWDA) is an organisation which enables and represents the collective interests of women with disabilities (self-advocacy) and works at a national and international level to promote, protect, maintain and ensure their human rights and fundamental freedoms (systemic advocacy) (2008, p. 2)

It is with this definition in mind that the Disability Resources section developed a modified model to provide students with the support they need to complete their study and to transition successfully into the workforce upon the completion of their study. This model is also based on a particular interpretation of social justice.

Social justice is sometimes defined as simply providing access to educational facilities for those who might not otherwise have access. “Often, policies of integration have been promoted which are based on a narrow conception of social justice defined simply as a matter of the rights of students with disabilities [or illness] to have access to regular [learning facilities]” (Rizvi & Lingard, 1996, p. 25). Social justice defined in this way often neglects to look at the entire experience and context of the student with disability and account for the range of difficulties they face. The ubiquity of these narrower interpretations of social justice can mean that the practical application of sociological theories, such as social inclusion, to the real world is often met with disregard and scepticism by those who consider themselves to be normal. The gap in social perception as it relates to ways of providing social justice for students with disabilities is a serious issue facing universities and other institutions, particularly given increased prevalence of mental illness (Australian Bureau of Statistics, 2012) and chronic illness in Australia and elsewhere .

We know chronic illness is increasing, [and that it] can be problematic for individuals affected, we know many people who work are likely to have chronic illness (either now or in the future) and we know few are likely to disclose the nature of stigmatising illness (Vickers, 1997, p. 248).

Failure to disclose, for people with an invisible disability, is often caused by their desire to appear to be normal. However, it is often difficult for people with disability to appear normal all of the time while they are at work. If they can manage the expectations of a workplace as

well as their disability, workforce participation has been shown to have positive outcomes for individuals with disability (Australian Institute of Health and Welfare 2009; Council of Australian Governments 2011; Department of Education Employment and Workplace Relations 2009). The social model of disability defines disability as a social construction.

The social model sees ‘disability’ is the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers. It therefore carries the implication that the physical, attitudinal, communication and social environment must change to enable people living with impairments to participate in society on an equal basis with others (People with Disability Australia, 2014, p. 1).

Individuals with disability, who are currently in the workforce, are subjected to attitudes of others who have no intention of adjusting their attitudes to accommodate the needs of those they perceive to be different. Organisations assess the knowledge, skills and abilities of their employees and may consider other irrelevant personal attributes such as disability.

It would be ideal if all organisations were willing to accommodate the needs of employees with disability, however in many circumstances employees are expected to conform to expectations of normality. Normalisation is a difficult concept for people with disability, and as the social model suggests some understanding is needed from managers and colleagues to assist with improving attitudes towards employees with disability. However, normalisation is exactly what is expected of people with disability in their places of work. Once students have graduated they move into an environment where disability might not be viewed as diversity but as a disadvantage. These people learn quickly about managing the way they appear to others.

Layers of management

The processes that students and employees undertake to manage their disability, study and university or work factors include: negotiating the self, managing the self and managing others. These layers were identified from the responses of students. *Negotiating the self* involves managing “their self-perception or beliefs that may have a positive or negative impact on their experience as learners” (Werth et al., 2014, p. 5).

Managing the self provides a basis on which students regulate the way they appear (Werth et al., 2014). Concepts of ‘passing’ or ‘covering’ (Goffman, 1986) form part of the process of managing the self. Passing is where an individual chooses not to disclose information about

their disability (where they have a choice). Covering is where individuals who have disclosed undertake certain actions to minimise the appearance of a disability. Goffman refers to these actions as “cosmetic techniques” (1986, p. 102). Aesthetic labour (Warhurst & Nickson, 2007), emotional labour (Hochschild, 1983) and emotion work (Bolton, 2005) also contribute to the suite of behaviours deployed to regulate the way individuals appear to others. Werth (2013a) consolidates these behaviours into two forms of work: asymptomatic work, which is the behaviours used to carry out responsibilities (at university) without the appearance of symptoms associated with a disability. Symptomatic work is the undertaking of responsibilities while a disability is apparent. It involves the management of physically obvious symptoms to preserve the individual’s capability (Werth, 2013a).

Management of others comprises the strategies students use to manage their disability in any social setting (Werth et al., 2014). Management of others may be undertaken using asymptomatic or symptomatic work and in addition adaptive work may also be utilised. Adaptive work is the means by which students seek adaptations from their lecturers. It is defined as “engaging with others in order that they or the organisation adapt in some way to the needs of the person with a disability. Adaptive work is used by students who require some form of adaptation or accommodation to assist with managing their study and their disability” (Werth, 2013a, p. 48).

About the project

This research project deployed both quantitative and qualitative research methods. There were 33 participants, the gender split was approximately equal. Participants were accessed after they had initially registered with Disability Resources. Students registered a variety of disabilities, including medical conditions, psychological conditions, neurological conditions and physical disabilities. Participants were enrolled in both undergraduate and postgraduate courses and across all Faculties. The data from this project has been reported in a number of publications, including: Lawson, Werth, Dunn & d’Abadie (2008), Hammer, Werth & Dunn (2009), Hammer, Werth, Dunn, Lawson & d’Abadie (2011), and Werth (2012). A common theme of the data was the appreciation the students expressed for the support they received through Disability Resources. In this chapter, the key data is from qualitative survey comments and the reflections, as recorded in her notes, of the Disability Resources Co-ordinator looking back on the supports that have been provided for students in the past and the way that the Disability Resources have adjusted their services in order to provide support

as well as assist the transition from University to the workplace through training in self-management and resilience.

Data was collected over three years, with students being asked to complete an initial survey after they first registered with Disability Resources, a follow-up survey towards the end of their first year. In their second year, they completed a survey which consisted of a series of open-ended questions describing their student experiences. At the end of the project students completed a survey which was similar to the initial survey. The survey instruments used open and closed questions to gather a variety of data. This paper focuses on the students' qualitative comments from these surveys. The open ended questions were analysed by them and the social model of disability was used as a lens to analyse the data. A limitation of this project is the use of reflective data and also the fact that it is too early to survey students who will benefit from this modified model upon their entry to the workplace.

Supporting students

One of the functions of Disability Resources has, in the past, been to help students deal with issues that may present barriers to their learning. Students in the study reported many positive experiences with the supports provided by Disability Resources:

I do appreciate having Disability Resources aware that I could be in need of assistance, I find this quite reassuring. [Student 2]

Like anything, or any place, there are staff that are extremely helpful and that is always appreciated and a breath of fresh air. [Student 14]

Many of the students in the study had good grade point averages, and some of them excelled in their chosen course of study. This suggests that the supports available to them assisted to mitigate any disadvantage that they experienced in their university studies because of their disability. This is an excellent outcome for the Disability Resources section. Developing appropriate ways to respond to the socially disadvantaging attitudes of others is an important feature in the supports provided for these students. Advocacy for students with disability also forms part of the Disability Resources brief who support students through processes which might disadvantage them without support.

Students may also be provided with tools which assist their learning and include specific types of technology, such as, Dragon - a speech to text program, or Jaws - a text to speech program for use by visually impaired students. Those who are unable to write or process information quickly in a lecture setting may also need the assistance of a scribe. These

students highlighted their difficulties and how these problems affect how they felt and their studies.

When attending a class, without note-taking, it is very difficult to get a lot of valuable information from the lecturer. To reach my full potential in my study, I have to spend more than double the time and effort to learn [compared to] normal students. [Student 36]

Formal supports such as note-taking or transcription, mitigate the disadvantages that they experience. Disability support workers can be accessed for a variety of purposes, including the following: assist with print disability, assist with organisation and motivation, to assist with access to computer based information systems and the library.

Studying in a tertiary environment, where high achievement is expected and normalcy is identified by independent learning, brings with it policies and attitudes which might be difficult to manage for students with disability. The various supports provided by Disability Resources assist with these, particularly their advocacy role.

I have been to two previous unis. The services at [University A] were okay, adequate. Good, but not brilliant. [B] University was a disaster. The services there were not at all adequate. It was a disgrace: unprofessional, grossly lacking and inadequate. I spoke to numerous students who had the same experience. [This university] is a more supportive environment - the policies are designed that way. It's a smaller, more compact, regional setting. The lecturers are there for you and with you. The learning process is involved. The learning experience is more positive. [Student 17]

The supports available at the university suit a variety of disabilities, for some students they chose to study at this particular university because courses were available externally. For this student the Tertiary Preparation Programme was useful, and together with a variety of support people had made a successful transition to tertiary study.

Prior to studying at [this university], [my disability] affected my study 90%, but now... it's about 25%. It used to be very debilitating regarding my employment, marital relationship, and studies... I sorted out family matters, relinquished a number of stresses, did the Tertiary Preparation Course, got myself into the zone to study, went to [university] open days, spoke to lecturers, saw people at Student Services, and sought advice from a medical team (GP etc). [Student 30]

The experience of this student shows that institutions would do well to consider more creative solutions than current strategies of offering adjustments and accommodations to address the social, familial and temporal challenges students face (Sachs & Schreuer, 2011). Indeed, a successful university life experience goes beyond the university into the community. The skill building supports and training provided at this university support students to develop their own strategies to succeed in their studies and make a successful transition to the workforce.

Training in resilience

Students who register with Disability Resources may receive support in a variety of areas. According to the Disability Resources Coordinator (DRC),

During the student registration interview the needs of the student are determined. Students are often identified as having difficulties with;

- *planning and organising study tasks,*
- *keeping to task,*
- *meeting deadlines,*
- *being unsure of how to unpack or work through study materials,*
- *lack of familiarity with the online study desk environment, and online forums for courses, and*
- *University systems, such as email, online assignment submission, turnitin.*

Helping students to address these difficulties might also include assisting students with the social challenge of disclosing their disability in a different environment. Disability Resources not only facilitates contact with lecturers, it provides training in developing confidence in advocacy, self-advocacy and resilience building (as reported by the DRC). The DRC points out that,

the lack of these skills can be varied, both because of the inherent nature of the disability (ADHD, ASD) or as a consequence of the disability and a feeling of being unable to do these things, caused by symptoms such as anxiety or chronic pain.

The role of study support workers

Study support workers are not content experts and only provide coaching (process based) assistance in the areas stated previously, although they may also act as a sounding board or guide for the student when looking at content in relation to a course. They would always encourage a student to seek further clarification from the lecturer. Depending on the individual student, a weekly time is provided for the student and study support worker to meet and commence working through the above and developing actions and reviewing tasks weekly. Support workers have been able over a number years (either because they are former students or have worked in the area for some time) to help and guide and coach the student over the course of their learning journey. Nonetheless, there are clear boundaries and any assignments must be the work of the student.

Committing to the sessions and completing weekly tasks is important. If students do not attend regularly, then sessions are cancelled. If they do not come prepared for the session, it cannot be completed before the allocated time. The student needs to remain responsible for their learning and they need to have ownership of this. Some students have no formal method of time management whether this involves using a diary, calendar etc., and it becomes one of the first things to determine: to have a student identify how they are going to track and keep to task, choose a strategy and start to develop their use of it. The ultimate goal of Study Support is to develop students' resilience and capacity for self-management which enables their coach to reduce contact hours per week from two or more hours a week in the first semester to one hour a week for a quick overall catch-up or review by semester three. Variations to this timeframe may stem from the point at which a student decides to present to Disability Resources. It is not unusual for students to present to Disability Resources after a semester of studies where they have struggled to manage and succeed because of the above factors.

The study support model and layers of management concept

Previous research has shown that students with disabilities must deal with different layers of management to succeed in their studies (Werth et al., 2014). The Study Support model discussed here addresses students' needs in this domain by supporting them in the development of relevant strategies, and the level of resilience required to succeed in their studies.

Having recently been diagnosed with [a long term illness] I have been on a huge learning curve to learn ways to overcome the effects of the disease on my personal, professional and academic life. [Student 33]

This student highlights the impact that his illness has on the various aspects of his life.

Study support sessions cover such topics as: how to manage study (time management, planning and organising, writing skills, research skills, assignment planning) and the management of work, life and study. They enable students to focus on their studies and where students engage these sessions have positive outcomes.

Staff have been absolutely wonderful with their support and guidance and have always acted both professionally and empathically towards helping me complete my studies. [Student 33]

Managing the reactions of others forms a part of the role of individuals with disability. These students are provided with the skills needed to undertake adaptive work. Adaptive work is defined as engaging with others in order that they or the organisation, adapt in some way to meet the needs of those with disability (Werth, 2013b). Because students need to develop skills which enable them to seek adaptation both for their studies and their future careers, the disability support workers provide training and support to develop skills in resilience and ways to manage the perceptions of others regarding their disability. We know that individuals with high levels of power are more successful in achieving the adaptations they require, while at university this ‘power’ is available through the support and advocacy from Disability Resources. Students commented on the value of this support:

[I have] more confidence and motivation to keep going on with the course & complete the degree [it is] easier than without disability support. [Student 36]
To complete the degree without support, would have been an impossible feat. [Student 8]

Developing skills in resilience, that is, how to cope with adversity is important where students have a stigmatised illness. It assists them with coping with negative reactions they may encounter in any sphere of their lives. “Students with disabilities face... attitudinal barriers within the university environment” (Stanley, 2000, p. 200). The resilience development also provides support when approaching lecturers for help. This type of support fosters the skills needed for students to self-advocate. It is generally expected that students will outgrow the need for this form of support once basic study skills have been developed

and students have a capacity to organise their own study. Developing resilience and self-advocacy are important in building the skill set which facilitates student success in the studies and assists in their transition to the workforce.

Negotiating the self

Students may need assistance with managing the difficulties of their disability. The following student comments highlight the impact their medical condition has on their ability to concentrate.

It [the disability] has quite an effect on my concentration in lectures. Sometimes I'll be in a bad state and have to attend an important lecture and it's really hard to concentrate. It's difficult to link things together. I'm quite affected at certain times. I'm affected at different levels at different times. [Student 9]

These circumstances have the potential to impact on the learning experience of these students. Disability Resources provides a holistic type of support which encourages students to access medical and support resources which enable students to best manage these types of situations.

Managing the self

Individuals with disability also need to learn how to regulate the way they appear in order to achieve the best outcomes. Students may have to modify their academic goals in order to study with a disability. These students have adjusted their goals in order to achieve their academic objectives:

I'm a high achiever but I don't set such a high bar anymore. I'm more accommodating to my medical condition. [Student 22]

Being willing to accept outcomes, which may feel somewhat lesser by their previous academic standards, may mean that students have difficulty finding the confidence to present themselves to lecturers with special requests. The training provided by Disability Resources assists with self-advocacy and advocacy where students need assistance in this area.

Management of others

Disability Resources resilience training provides students with techniques and skills necessary to negotiate many kinds of social situations at university. It also gives students the necessary study skills to manage university level study and the transition into the workplace. Students comment that:

I feel a lot better to know I'm supported. Before, I felt like an outcast, but now I feel more welcome. [Student 1]

Knowing and feeling supported and having understanding from the lecturers is a really good thing. [Student 9]

I believe the university has worked extremely effectively with my situation. [Student 16]

Students may not realise the personal effort required to negotiate the self, manage the self and manage others while undertaking their university study. The role of Disability Resources is designed to mitigate the difficulties they might experience. The innovative support not only helps students learn to cope with the 'layers of management' required while at university, but it gives them skills which are transferrable to the workplace at the conclusion of their studies. The value of providing these skills cannot be underestimated.

Conclusion

University study is challenging for many students, for those with some additional disability the task may seem insurmountable. A Disability Resources support program such as the one described here is important for developing capacity rather than service provision, facilitating not (just) advocating, encouraging rather than pitying. A student with disability who leaves university with skills in self-advocacy and multiple techniques for resilience building may well be better equipped for the workforce than students with a disability who have not had this specific type of coaching and resilience building.

References

- Australian Bureau of Statistics. (2012). 4338.0 Profiles of Health, Australia 2011-2013: Australian Government.
- Australian Institute of Health and Welfare, *Chronic disease and participation in work*, 2009, Canberra.
- Bolton, S. C. (2005). *Emotion Management in the Workplace*. Gordonsville: Palgrave Macmillan.
- Council of Australian Governments, *National Disability Strategy 2010-2020*, 2011, Commonwealth of Australia, Canberra.
- Department of Education Employment and Workplace Relations, *National Mental Health and Disability Employment Strategy*, 2009, Federal Government, Canberra.
- FaHCSIA. (2012). National Disability Advocacy Program. Retrieved from <http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program>

- Giddens, A. (2009). *Introduction to Sociology*. New York: W. W. Norton.
- Gillies, J. (2012). University graduates with a disability: the transition to the workforce. *Disability Studies Quarterly*, 32(3).
- Goffman, E. (1986). *Stigma: notes on the management of spoiled identity*. New York: Simon & Schuster Inc.
- Hammer, S., Werth, S., & Dunn, P. (2009). *Tertiary students with a disability or chronic illness: stigma and study*. Paper presented at the Enabling Pathways: 3rd National Conference of Enabling Educators, , Toowoomba.
- Hammer, S., Werth, S., Dunn, P., Lawson, K., & d'Abadie, D. (2011). Expectations of ability and disability at university: the fine art of managing lives, perceptions and curricula. In W. Midgley (Ed.), *Beyond Binaries* (pp. 211-220). Toowoomba.
- Hochschild, A. (1983). *The managed heart: commercialisation of human feeling*. Berkeley: University of California.
- Lawson, K., Werth, S., Dunn, P., & d'Abadie, D. (2008). *The learning experience of students with disabilities and long-term medical conditions at USQ*. Paper presented at the Pathways 9 Conference, Melbourne.
- People with Disabilities Australia (2014). The Social Model. Retrieved from <http://www.pwd.org.au/student-section/the-social-model-of-disability.html>
- Rizvi, F., & Lingard, B. (1996). Disability, education and the discourses of justice. In C. Christensen & F. Rizvi (Eds.), *Disability and the dilemmas of education and justice*. Buckingham: Open University Press.
- Sachs, D., & Schreuer, N. (2011). Inclusion of students with disabilities in higher education: performance and participation in students' experiences. *Disability Studies Quarterly*, 31(2), 1-20.
- Stanley, P. (2000). Students with disabilities in higher education: a review of the literature. *College Student Journal*, 34(2), 200-211.
- Vickers, M. (1997). Life at work with 'invisible' chronic illness (ICI): the 'unseen', unspoken, unrecognised dilemma of disclosure. *Journal of Workplace Learning*, 9(7), 240-252.
- Warhurst, C., & Nickson, D. (2007). Employee experience of aesthetic labour in retail and hospitality. *Work, Employment and Society*, 21(1), 103-120.
- Werth, S. (2012). Negative Events, Positive Outcomes: Improving Labour Force Outcomes via Tertiary Study for Individuals with Disability and Chronic Illness. *Australian Bulletin of Labour*, 38(4), 345-366.
- Werth, S. (2013a). *An investigation of the interaction of chronically ill women and their working environments*. (PhD), Griffith University, Brisbane.
- Werth, S. (2013b). *Working with chronic illness: a new perspective*. Paper presented at the 27th Conference of the Association of Industrial Relations Academics in Australia and New Zealand, Perth.
- Werth, S., Hammer, S., & d'Abadie, D. (2014). Disability and study: layers of management. *International Journal of Pedagogies and Learning*, forthcoming.
- Women with Disabilities Australia. (2008). The role of advocacy in advancing the human rights of women with disabilities in Australia. Retrieved from www.wwda.org.au/advpolpaper08.htm