Work Transitions Narrative

Preamble: Post reflective question developed by column editor Lynn Shaw

Each account of navigating the consequences and impact of newly acquired limitations is unique and also situated in the normative expectations of society and the authoritative knowledge of others. This was the case for Anna as she dealt with the personal challenges of a brain injury and the external pressure to relinquish dreams and goals related to career paths. Encounters with others who are in a position to give advice in school to work transitions bring with them knowledge that can rule how they guide students with and without disabilities in preparing for work or careers. For Anna the challenges were accessing the supports she needed to achieve her goals rather than being redirected to settle for less about her potential and future academic performance and career potential. Anna tapped into all of the educational resources and supports as well as to knowledge of rehabilitation professionals to transform, adapt and adjust to new ways to learn, take notes, think, retrieve information, process, coordinate, plan and use multiple sources of data etc. Her current involvement in a research study opened a door where she is gaining further experience and skills in scholarship. All of these are possible pre-requisites for her transition to a future career/work. Please read her narrative and review the post reflexive questions to help you reflect on the internal resources and situational catalysts that propelled Anna forward in managing steps toward success in being able to live, learn and work with the consequences of a brain injury.

Overcoming No: A firsthand account of brain injury rehabilitation in the context of education and school transitions

Anna Saucier

E-mail: Anna.Saucier14@gmail.com

It was a Tuesday evening, September 13, 2011. There were two minutes left on the clock during an ordinary soccer game of my sophomore year of high school. A player on the opposing team had a breakaway toward our goal with only myself between him

and our goalie. With only stopping the ball in mind, I sprinted across the field and slide tackled the ball away from the opponent. This collision caused the other player to flip off his feet with his knee finding its way directly into my left temple. I immediately knew something was wrong. I had previously sustained seven other concussions from various different activities, although they were all very minor, yet I knew this one was different. I stood on the field as the game ended, disoriented and confused. I walked off toward my coach, high fived the opposing team, then collapsed on the ground.

An ambulance ride to the local hospital and a CT scan suggested I not only suffered a concussion, but I potentially had a brain bleed. With the rural hospital being ill equipped, I was transported by ambulance to the larger hospital an hour away. After a stop in critical care and more testing, the doctors ruled out a bleed, but did admit me due to the severe headaches I was having. Four days later, I was released from the hospital and went home where I was told to rest. After two weeks of coloring, playing simple board games, and mostly sleeping, not much progress had been made in terms of recovery. I had to stay on a strict schedule of pain and anti nausea medications to keep from being in agonizing pain. I was unable to walk without assistance, ride in cars in an upright position, and I wore sunglasses at all times. An appointment was scheduled with a local neurologist that specializes in sports injuries. Through ImPACT testing, a neurocognitive assessment administered on a computer that measures working memory, attention span, sustained and selective attention time, reaction time, and nonverbal problem solving [1], he determined that although I was only slightly below or right around average on all the sections of the assessment, these results did not align with my academic ability before the accident. Therefore, he recommended I have further testing done by a neuropsychologist.

Navigating High School

While waiting for my next appointment, the first meeting addressing my academic future occurred. In a meeting with some of my teachers, a guidance counselor, the dean of students, and my parents, it was determined that a Medical 504 Plan should be established while I recovered and the severity of my injury was determined. A Medical 504 Plan allows for students with medically diagnosed disabilities to receive accommodations that will allow them to have academic success [2]. The aforementioned team also suggested I attempt to attend tutoring sessions for one hour every weekday I was feeling well enough to. These sessions were where my discrepancies really began to show themselves. I was not able to read, write, or perform basic math skills. My ability to remember things I was told or had read was almost nonexistent. I even lacked the stamina to function through the entirety of a one hour tutoring session. These deficits, along with many others, were confirmed through the results of two days of neuropsychological testing [3]. When being told of the results, I encountered the first of many people who would try to convince me to minimize my goals and dreams due to their perception of what they thought I was capable of. When my parents asked about how I should proceed in regards to my academics, the neuropsychologist explained that I should try to just get through the work and be okay with getting B's instead of struggling and working toward getting A's. I started crying, not out of sadness, but out of pure anger that someone thought I should compromise my academic pursuits to just float by. Not only would I not settle for B's, I used this comment to motivate me to achieve at the highest level I was able to.

Over the next few weeks, while still seeing very little improvement, shifts began to occur when it came to my schooling. I transitioned from a Medical 504 Plan to an Individualized Education Program, or IEP, due to the severity of the injury. The IEP would not only allow for accommodations like the Medial 504 Plan does, but also for specialized courses and services specific to my new-found disability [4]. I still was unable to attend regular classes. However, I was able to switch tutors to someone I had worked with in the past through the Gifted and Talented Program, a series of small, additional classes for students who excelled in mathematics and/or language arts. She not only had prior experience working with me, but also had personal experience with an acquired brain injury. I believe without the support and experience from this tutor, I would not be where I am today. Determination to not let this injury define my future drove me to focus on my rehabilitation. I worked to reduce my light sensitivity in order to be able to drive. I began to reintegrate myself into the many leadership roles I filled at my school in order to regain some normalcy. While I worked towards regaining basic abilities, I saw a neurologist at Boston Children's Hospital. Apart from adjusting my medications for the constant headache I was having, she also suggested I seek relief through alternative methods. The pursuit of finding relief for my ever-present headaches was integral to my recovery since the pain played such a large role in why I had difficulties with reading, attention, and overall stamina.

In December, I began seeing a chiropractic neurologist who was located an hour and a half away. With visits twice a week for about three months, I began to see slight improvements in my headaches since they discovered I had restricted blood flow to my brain and pinched nerves. The chiropractic neurologist utilized physical rehabilitation, muscle stimulation, proprioceptive neuromuscular facilitative stretching, spinal traction, and chiropractic adjustments throughout the course of treatment [5]. These services helped correct any physical factors that were contributing to my headaches.

Now that I had retired the sunglasses, some of my peers, teachers, and administrators began to believe that I had recovered. Since I looked "normal", I must have healed. That was simply not the case. Throughout the rest of my high school career, myself and a trusted few around me that understood what having a brain injury entailed, had fight with the rest of the administration and teachers to get me the accommodations that I needed. In meeting after meeting for my IEP, there would be arguments about what I really needed and how bad my condition was. In one of the most memorable meetings, my mother couldn't be there due to having to take so many days off of work already to care for me, so my father attended. Most of the special education staff, teachers, and administrators were attempting to reduce my tutoring, changing expectations for what I would achieve to things that were just not realistic. Making the situation worse, I was having a "bad brain day" and was struggling to advocate for myself. My father listened to the disagreements between those that understood and those that didn't. When asked for his input he simply explained that even though he struggled to understand what I was experiencing and how I could appear to be "normal", he trusted and believed that I was the only one who could truly know what was going on in my own brain. These few sentences not only brought almost everyone to tears, but also helped people understand that it was not their perception of where they thought I was that mattered, but rather

what I was experiencing. Even though I still had to fight every step of the way, sometimes winning and sometimes losing, this one conversation helped shift the mindset of those that doubted me.

Despite this battle being won, an even more impactful one was right around the corner. The director of Special Education at my school had suggested I meet with a vocational rehabilitation provider to determine how they could assist me in transitioning toward my goal of attending college. An introductory meeting occurred and I expressed my goals for attending school out of my home state of Maine as well as completing the course work to attend medical school in the future. The vocational rehabilitation provider expressed that it was not realistic to set my goals so high, that I should attend a state school in order to receive help from their department, and I should change my career aspirations. Once again, I found myself in tears. My identity of being an athlete had already been stripped from me, therefore, I was not going to let my lifelong dream of becoming a doctor be taken from me as well. I continued to focus on my recovery and do everything possible to complete all the necessary steps in achieving my previously mentioned goals.

To continue with my recovery, I enrolled in physical, occupational, and speech-language therapy at a Neurorehabilitation center. In physical therapy we worked on improving my balance, hand-eye coordination, vertigo, and ability to perform cardio without inducing a severe headache. In occupational therapy the therapist addressed my headaches, which were causing the major disturbance in my ability to attend classes by performing craniosacral therapy [6]. The occupational therapists also addressed my inability to hold onto writing utensils by having me use a weighted pen. Within a few weeks I never unintentionally threw a writing utensil again. Lastly, the speech-language pathologists taught me word retrieval strategies along with new techniques on how to approach reading and writing, the two academic areas that I had the hardest time with. These techniques included writing outlines for papers and trying a variety of diagrams to follow character development or plot lines throughout a novel. These techniques took the pressure off of my memory and also played to my strength of being a visual learner. Although I have improved greatly since this point in time, I continue to use many of the strategies I learned in my academic life at the collegiate level.

Over the course of the next few months, I began attending classes one at a time. I continued with my

Neurorehabilitation and tutoring. As time passed, I continued to improve and experienced minor setbacks from time to time. In June, nine months after the trauma occurred, I was driving to school and came to a major realization as I pulled into the parking lot. I was headache free. I immediately called my mother, the one person who never doubted and always supported me, to tell her the news. I began to cry, which, in turn, triggered a headache. However, this brief pain-free window showed me that being headachefree was possible. During the course of the next year and a half, I worked diligently with my tutor, graduated from occupational, speech, and physical therapy, began attending more and more classes, and regained normalcy in my life. I was able to rejoin all the clubs I had previously been a part of, was accepted into the National Honor Society, and found a new passion in the drama club. I participated in the normal activities for juniors and seniors such as taking the SATs, attending prom, and applying to colleges, none of which were in Maine. I continued to search for relief for my headaches that still plagued my everyday life even though they had decreased in intensity and frequency. I tried acupuncture, massage therapy, and Reiki. All relieved my headaches to some extent, yet none were a cure-all [7–9].

By the end of my senior year, I had accomplished what very few people thought I would. I graduated from high school, not only on time, but in the top portion of my class. I had been accepted and would be attending Boston University. I regained almost all skills and abilities I had lost either in their original form or by finding new approaches. Although I was very excited to start my new journey in Boston, I was worried about how I would perform away from my support system that had been so integral in my success since my brain injury.

Moving forward with College

During the summer before college, I contacted the Office and Disability Services at Boston University. In contrast to my previous experience at my rural high school, Boston University was easy to work with and thorough in providing me the appropriate accommodations that would help me succeed throughout my college education. These accommodations included having extended time for exams, taking exams in separate, distraction reduced environments, having a peer note taker for my courses, being able to record lectures, and having excused absences when I experi-

enced crippling headaches, which although happened much less frequently, still happened. These accommodations have proved critical to my success as a student. Although I try to limit their use, it is nice to know that I am supported in my academic pursuits.

Also through the Office of Disability Services, I was informed about a research study that was taking place at Boston University called Project Career. Project Career works toward helping college students with traumatic brain injuries successfully navigate and excel in college and find employment once they graduate [10]. I decided to find out how this study could benefit me and ultimately decided to enroll. Through the support of a coordinator in the program and the iPad that is given to all participants in the study, I had found a support system in Boston. Not only did the coordinator provide applications suggestions to help in areas where I struggled in terms of academics, health, and everyday life, she also acted as a sounding board to express my frustrations, struggles, and achievements.

One example of an application that I use on the iPad is Notability [11]. Notability is a note-taking app that allows the user to take handwritten notes on the iPad while also recording and syncing audio with the notes. I attribute this application to a lot of my success in college. Not only was I able to take notes using different colored ink which played to my visual learning style, I also knew that the recordings would serve as a back up on days when my brain was not functioning well enough to be trusted to take accurate notes. Additionally, I use an application called iStudies Pro that works as a calendar and planner all in one [12]. Every semester I am able to add my classes and their locations along with imputing assignments with their due dates and exams into the one program. Reminders can also be set for classes, exams, and assignments. This application has been very useful not only in helping my organization, but also in supporting my memory. I do not have to trust my brain to remember my classroom locations or when homework assignments are due. This is very important since I find that the more I can rely on applications or supports outside of my brain for memory, the better my brain functions. This application also seamlessly syncs with my personal calendar so everything is combined and I do not have to juggle multiple sources of data.

Project Career has also helped in career pursuits with assistance in creating and updating my resume, locating internships, and providing me with a mentor. I have been able to give back to Project Career by becoming a research intern where I have presented a

poster at an academic conference on brain injuries, helped recruit new enrollees by being interviewed in an article for BU Today, and assisted other participants in learning to use different apps on their iPads.

Now in my junior year of college, I am preparing to finish my pre-med course requirements. I have only a few quirks left from my mild traumatic brain injury and the post-concussive syndrome aftermath. I am involved in my school community and have employment throughout the school year while balancing a full academic course load. If you would have asked most people in my life after the injury if I would be where I am today, they would probably laugh and say no. However, there was never a doubt in my mind that I would persevere through the challenges and doubts of others to achieve my goals in life.

Post Reflexive Questions:

- 1. In this narrative there are catalysts (positive energy that helps a person to adapt or change) as well as well as catalysts that are perceived as highly charged situations that force a person to face change that is not necessarily wanted. Identify the catalysts in this narrative that supported or were instrumental in moving Anna to prepare for education, which ones helped her prepare to address challenges in her education, and the challenges of living and lifelong learning with a brain injury?
- 2. Experts or those with authoritative knowledge are important to persons in accessing resources needed to transform their lives. In this narrative there are several instances where Anna interacted with persons who have the power of knowledge and potential access to resources. In Anna's narrative the experts develop views and knowledge that is shaped by normative expectations of society about 'normal' and by experiential knowledge and expectations about 'brain injury' and consequences for human potential, as well as policies that render access to educational special supports/resources. Given that you live in context that is situated by local or regional geographical, political or cultural differences explore how they enter into the views of experts and resources that may limit or promote a post-secondary students' capacity to adapt, transform or flourish in higher education and

then the impact and consequences for success in future career entry and transitions. For the limiting factors discuss how you might work to advocate for changing views and ultimately policies to promote opportunities for school to work transitions.

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