

Lindsey Pampanye

From the U.S. to Ireland with Hydrocephalus

ireland

My first experience with international exchange was as a child when my family in the United States hosted students from Belfast, Northern Ireland through the Pro Children program. Staying in touch with one of our visitors throughout the years had always left a lingering desire to explore my Irish roots and travel in the opposite direction, but the trip was never a forgone conclusion.

My Chronic Health Condition

I was born with Hydrocephalus which is a neurological condition that causes an abnormal fluid build up in the brain that can be fatal if untreated. The Hydrocephalus experience varies greatly from person to person but the most common treatment is a surgically implanted device called a shunt. There is no known cure. At the time I began pursuing international education after college, I had 6 total brain surgeries, all during childhood, all emergencies.

Lindsey celebrating graduation day from the MSc Equality Studies Programme at University College Dublin.

Lindsey at the Giant's Causeway, a UNESCO World Heritage Site in County Antrim, Northern Ireland.





Feeding donkeys while traveling the Ring of Kerry in County Kerry, Ireland.

The idea of leaving my support system elicited many doubts. Could I get my medications? How could I afford it? Who would help me if I got sick? Over time I would come to see these questions as starting points rather than disqualifications.

A series of small steps made an impossible international move suddenly seem manageable. I started as a resident student during my undergraduate studies. In time I took trains and planes independently, went to doctors' appointments alone, and did a post graduate service program out of state. These deceptively minor accomplishments built on one another and, eventually, a chance conversation with someone visiting New York from Ireland was the push I needed to start researching programs, and it wasn't long before I found a match.

The Equality Studies Programme at University College Dublin (UCD) was a unique combination of everything I enjoyed, wanted to learn about, and hoped to pursue as a career. I was immediately sold and on the path to Dublin.

From Non-starters to Starting Points

A key part of my research was taking the time to reflect on my personal parameters for going abroad. I needed certain medical facilities. I only spoke English and I didn't feel comfortable translating my needs, especially in an emergency. I had a deadline to finish my degree to keep my teaching license, and I also wanted to complete school before aging out of my parents' health insurance plan.

Managing my disability while abroad became a degree program on top of my masters. As a disabled non-EU student, I found applications, immigration, student loans, and travel processes fraught with institutionalized barriers. I had to source new doctors, navigate the immigration system, and do all of this on top of finishing grad school and also trying to immerse myself in a new culture. Honestly at times it felt impossible – and realistically, it was. Spoon Theory really helped me to understand why (read more about Spoon Theory on page 9). I only had so much of myself to give on any day. I was familiar with the saying “you can't pour from an empty bucket” and it's incredibly accurate.

However, I was well connected with pre-departure support like my local UCD Global Centre in New York and eventually the UCD Access and Lifelong Learning Office, as well as resources from the NCDE that were incredibly useful at all stages of my exchange. I consulted directly with my medical team but had also contacted Spina Bifida Hydrocephalus Ireland to better understand the local culture as it relates not only to my condition but disability as a

How a Sunflower Promotes Accessible Air Travel

Some people with disabilities may require reasonable accommodations when they travel. Disclosing a disability can be challenging, and this is often amplified when a person's disability is not visible. The Hidden Disabilities Sunflower program was created as a tool used during air travel for individuals to discreetly and voluntarily communicate to airport staff that they have a disability. By wearing the sunflower lanyard, you let others know that you might need specific assistance, understanding or just more time.

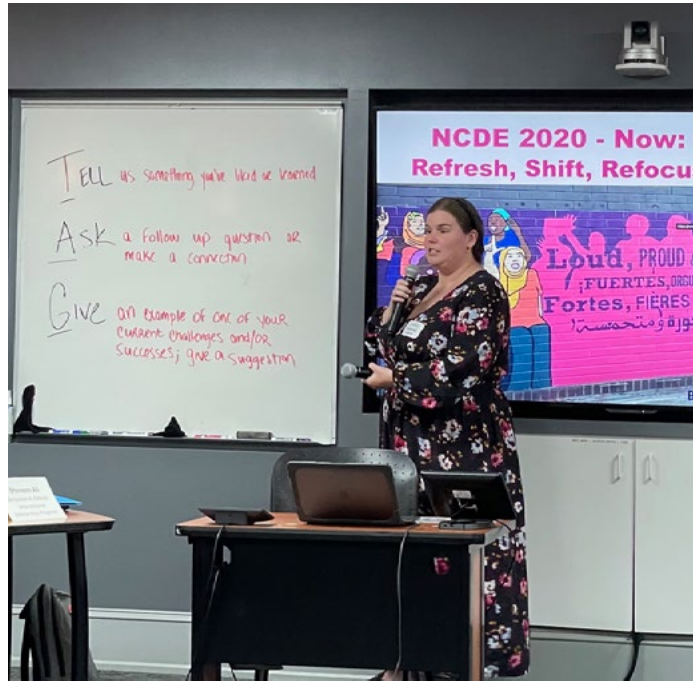
According to the program, the sunflower symbol was chosen as it is visible from a distance and suggests positivity and strength while being a joyful image. Visit the website at www.hdsunflower.com to read stories of other travelers,

find places that support people with non-visible disabilities, and locate participating partners where you can get a free sunflower lanyard to support you in your travels. More than 240 airports around the world have signed on to provide support for travelers with non-apparent disabilities through this program!



whole. Lastly, I was supported by my connection to the international Lasallian education network, a global collection of educational centers advancing the mission of St. John Baptist De La Salle to bring a quality education to those at risk of exclusion. Lasallians welcomed me to Ireland and continued to step in as a local “family” at all stages of my time abroad.

My key reasonable accommodations included receiving lecture slides in advance, recording my classes, and flexible deadlines. Part of my disability involves chronic pain and trouble sleeping, which can make following extended lectures difficult. Being able to review the content and really take my time with comprehension made a huge difference.



Presenting at a National Clearinghouse on Disability and Exchange event.



A visit to the Cliffs of Moher in County Clare.

The Unthinkable Becomes Thinkable

After completing my graduate school program, I continued living and working in Ireland on the 1G stayback visa which coincided with the COVID lockdowns. My worst case scenario - "what if I need brain surgery while abroad" - became significantly amplified. Now, it was "what if I need brain surgery during a global pandemic, in a lockdown, under significant travel restrictions." And ultimately it became my reality. After over 15 years of being surgery free I was glad to have taken the time to really, truly, plan for how I would successfully navigate falling ill abroad. My worst-case scenario really was incredibly manageable.

This is where I had the opportunity to really reflect on my experience with invisible disability. Nobody would ever know it's there unless I said something- and I often want to scream it. Despite having a chronic illness, I had never used reasonable accommodations in school or work unless it was related to surgery. Going abroad was the first time I asked myself, why would I only set myself up for success during the worst case scenario of being in the hospital? The day-to-day matters just as much.

The time and energy I dedicated to going abroad has made an incredible impact on me! I focused my thesis project on disabled international students in Ireland, my advocacy led to more healthcare options for internationals with disabilities, and I have found a career in inclusive international exchange. I look forward to contributing to a future where Disabled students can just be abroad and enjoy the program they're enrolled in without having to focus any extra energy ensuring it is accessible for them. ■

Spoon Theory Explained

Spoon Theory is a metaphorical framework first introduced by Christine Miserandino in 2003. The theory provides a tangible way to communicate otherwise abstract concepts about how many people experience disability, non-apparent disabilities in particular.

Spoon Theory uses spoons to describe usable energy where one spoon represents one unit of energy. Nondisabled people may typically expect an infinite number of spoons (or endless energy) to accomplish goals each day. Some Disabled people, however, start the day with a set number of spoons. Managing energy and resources requires a conscious, intentional effort. Disabled people might need to "hoard" or "sacrifice" spoons for tasks that nondisabled individuals may not need spoons for at all.

People with chronic illnesses may physically have less energy to use on a day-to-day basis. When navigating pain-related conditions it can be significantly taxing to complete deceptively "automatic" tasks like getting out of bed, brushing your teeth, or getting dressed. Or, consider the energy it may take for a person with ADHD to focus and participate in a conference setting with several back-to-back presentations.

Limited spoons does not need to mean limited opportunities to access international education. Balancing energy and self-care when abroad poses a unique challenge. Exchange participants often have to adapt to unfamiliar surroundings,

languages, and cultures. This can be physically and emotionally demanding for all people regardless of Disability identity, but becomes especially difficult when compounded with "low spoons." In these new environments, participants need to develop effective systems for managing their disabilities and ensure their well-being without exhausting their limited spoons. Effective communication of these needs is vital to avoid burnout and maximize experiences.

Spoon Theory can be an invaluable tool for participants on exchange. As a method for self-reflection, it helps to not only better understand and manage your energy levels, but also establish boundaries and create manageable schedules, and ultimately communicate these needs effectively to those around you. There is also a growing sense of community thanks to Spoon Theory! The concept of "Spoonies" is gaining popularity worldwide. Groups of Spoonies are becoming readily available both in person and online that make international exchange programs more inclusive and enjoyable for all. Before traveling look into joining the local group of Spoonies to learn more about the resources in the community or just to make a few friends.

Read this blog from a Spoonie who traveled abroad to learn more about their experience and a few tips to use on your own journey!