

Disability Disclosure in Personal Relationships



National Disability Mentoring Coalition's

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Partners for
Youth with Disabilities



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INTRODUCTION

This is a guidebook for transition-age youth with disabilities who want to learn more about how to navigate their disabilities in relationships. From friendships to the workplace, this guidebook provides both background and practical knowledge to help youth feel prepared to choose when, where, and to whom to disclose their disabilities. It also explores how to create and sustain healthy relationships after disclosure.

Chapter 1 provides a broad introduction to disability history, including topics that range from stereotypes to the Americans with Disabilities Act. Chapter 2 examines popular media portrayals of disability and outlines ways to approach disability disclosure in personal relationships, especially when the person who is being disclosed to has misconceptions about disability. Chapter 3 explores disability disclosure in the workplace by defining key terms related to disability and employment, detailing the rights of workers with disabilities, and explaining the discrimination complaint process. Chapter 4 discusses navigating personal relationships when more than one person has a disability, and Chapter 5 describes how to find creative solutions to access needs in personal relationships.

The authors include research, personal experience, and links for further study to thoroughly, but not completely, cover this topic. We invite you to use the guidebook as a starting point in a lifetime of learning about yourself, your relationships, and how to create a good environment for yourself and those around you.



Image description: a wheelchair user looks at and touches a large vertical display.



Image description: A woman sits next to a man who uses a wheelchair and they both look at the laptop on his lap.

CHAPTER ONE

BY DASHIELL MEIER

I know what people might think: why am I discussing disability history? Well, I am talking about this because people in the public see people with disabilities.

One way and how far we have come to where we are today is thanks to unique groups who are actively helping pave the way to get our civil rights so I will be talking about the history behind it. I want to warn you that the content will get grim and dark.

Stereotypes

There are a lot of prejudices and stereotypes about disability in today's society, and that is true, but disability groups have been working on Education and employment, and more than proves that the myths about us are not valid. Some of these stereotypes are: that people with disabilities are not as bright as people without disabilities, that people with disabilities always need help, and that curious children should never ask people about their disabilities. This goes to show that the wider public doesn't know how to act and respond to people with disabilities.



Image description: two women with brown hair and glasses look at one another and smile.

There is a lot of prejudice against and stereotypes about disability in today's society, but disability advocacy groups have been working to disprove these myths for years by working for advancements in education, employment, and more. Some stereotypes include people with disabilities are not as bright as people without disabilities, people with disabilities always need help, and curious children should never ask people about their disabilities. Generally, these myths show that the public as a whole doesn't know how to act and respond to people with disabilities.

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Disability Tropes

Now let's talk about disability tropes; when it comes to disability, in the media, people recognize disability as evil characters like Palpatine and Lord Voldemort from Star Wars and Harry Potter films. They share a common trope called disfigurement, and in this case, that is shown as evil because of how the heroes see these characters and reflect on how the public sees people with disabilities. It is crucial to think about history because by accepting the past for what it is, how else can we look past it and move on? Myths about disability can be seen in disability tropes in popular media. Often, people recognize disability in evil characters like Palpatine from Star Wars and Lord Voldemort from Harry Potter films. These characters share the trope of 'disfigurement', which is supposed to show physically how evil the character is in the eyes of the hero. This also reflects how the public sees people with disabilities. It is essential to understand how these tropes are found in the media and how that connects to the history of disability because it can help us move forward.

When people see people with disabilities, they tend to think about the evil characters they know, and that is not a good way of thinking

because people with disabilities are not that way at all, but the issue is that is how the broader public sees disability these days. It is essential to understand that people in society should not judge a book by its cover. Knowing the history behind disability is an excellent start to making friends.

Friendships

When it comes to friendships, it can be even more difficult for children with disabilities because the non-disabled children would not know how to act and respond, and it can be scary for them because they only know what everybody else knows about disability and that can be difficult on its own and life is not an easy path for anyone but sharing our history can affect people because they have no idea what life is like for us so it is vital that they understand the history so it can help them understand us and it would be easy to make friends that way.

Making friends can be even more difficult for children with disabilities because non-disabled children may not know how to act and respond to children with disabilities. It can be scary for them because they only know about disabilities from the evil characters they have seen on TV or from the myths that the adults around them know. It is essential to share the history of people with disabilities with the non-disabled so that they understand what life is like for us and how our history has shaped our experiences. This would make it easier to make friends for children with disabilities.

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Language

Another reason for understanding the history behind disability is because of how people communicate with others. When people are being ableist verbally, they think it is ok for them to say those words, but they don't understand; for example, the R-word when it is used, people who have Down Syndrome will be offended because that word targets people who have Down Syndrome, but the public doesn't know that. The way to get around it is to tell them how you feel when they use that word and talk that way.

Another reason to understand the history of disability is to change how people communicate with others. When people use words that target specific groups of people with disabilities, they think it is okay to do so even though saying those words is ableist. For example, many people who use the R-word do not know that it targets people with Down Syndrome and that people with Down Syndrome will be offended by their use of the word. If non-disabled people knew the history behind their words, they would know how it makes people with disabilities feel when they use that word and wouldn't talk that way.



Image description: A person wearing a beanie hat and hoodie sits on the ground with their arms out and up in front of a blurred crowd of people who are seated and looking forward.

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Models of Disability

What are the two models of disability? That is a very interesting question because not a lot of people know about the social model and the medical model. Just to recap, the medical model is based around that the individual is a problem, while the social model is around that the person is not the issue but the barriers in today’s world. So, how does this relate to history? Well, for a long time, we have been segregated for far too long where we were living in asylums and being tested for vaccines just because of how people see us. One of the asylums, called Pennhurst, was turned into a haunted house where people dressed up as the people with disabilities who passed on back then. Because of how traumatizing our history was, but sometimes, when we look back at what happened, we can reflect on it as people move on in our lives.

There are two models of disability: the medical model and the social model. The medical model says that the individual with the disability is the problem, a problem that should be solved through medical intervention. The social model says that the ableist barriers in society are the problem, not the person with a disability, so the problem should be solved through removal of these societal barriers. For a long time, people with disabilities were segregated in asylums, where they were not treated well and sometimes experimented on. This follows the medical model and dramatically affects how non-disabled people see people with disabilities.

But wait, there is one more model of disability, and that is called the Functional model of disability. What is the definition of functional Disability? People may ask, This model is similar to the medical model in that it conceptualizes disability as an impairment or deficit. Physical, medical, or cognitive deficits cause disability. The disability itself limits a person’s functioning or the ability to perform functional activities.

Medical Model	Functional Model	Social Model
• Disability as a consequence of a health condition, disease, or caused by a trauma. • Disrupt the functioning of a person in a physiological or cognitive way.	• Disability is caused by physical, medical, or cognitive deficits. • Limits functioning or the ability to perform functional activities.	• A person’s activities are limited not by the impairment or condition, but by the environment. • Barriers are consequences of a lack of social organization.

Eugenics

Eugenics is a way where people control what characteristics children have at birth to “improve” society. It has been used as a reason to sterilize people with disabilities forcibly, put people in institutions, and terminate pregnancies.

When it comes to eugenics, how can we discuss it without talking about the Nazis? Hitler borrowed the concept of eugenics and used it in hopes of wiping out the Roma and Jewish people. He invented the gas chambers, tested them on children with disabilities, and killed them in large numbers.

Eugenics is a way that people try to control human characteristics in order to ‘improve’ society. Historically, this has been used as a reason to forcibly sterilize people with disabilities, segregate them into institutions, and to terminate pregnancies when the fetus has a disability. It is hard to discuss eugenics without talking about Nazi Germany. Hitler borrowed the concept of eugenics from American thinkers and used it to try to wipe out the Roma and Jewish people. He invented gas chambers, tested them on children with disabilities, and killed them in large numbers. Today, eugenics still plays out in society through things like refusing to take precautions in the middle of a pandemic because people with pre-existing conditions should just be killed by the virus and

selectively terminating pregnancies when the fetus has a disability.

Americans with Disabilities Act (ADA)

Now, let’s talk about the ADA and how it came to be. We all know that because of the ADA, we have protection for our rights to vote, get married, and more. One of our founding fathers of disability was Ed Roberts, who paved the way to influence change in our society. One crucial way he did that was in his school; he was in the hospital room, and people helped him. Sometime later, the Capitol Hill climb started with people with physical disabilities getting out of their chairs and crawling the steps of the Capitol building. All of this was influenced by how our history shaped society and began a new era where activists began speaking up for themselves, and we still are fighting the stereotypes about us even today

Recently, the Americans with Disabilities Act (ADA) has become a big part of disability history. The ADA protects people with disabilities’ right to access society as non-disabled people can, including protecting the right to vote, start families, and more. Ed Roberts is one of the people who paved the way for this significant change in our society. He started his activism in his college, but it quickly spread across the nation. After a while, people with disabilities participated in the Capitol Hill climb, where they got out of their chairs and crawled the steps of the Capitol building. This activism was shaped by disability history and began a new era of activism where people began to speak up for themselves more. We are still participating in this activism and fighting stereotypes today.

CHAPTER TWO: EXPLORING NON APPARENT DISABILITIES WITHIN MEDIA AND PERSONAL RELATIONSHIPS.

BY ALEXA DE ALEJANDRO

Disability in Media

When people think of the word disability, the image that often comes to their mind is people with physical disabilities or cognitive disabilities. People are often not aware that having a disability is far more complex because the idea that having a disability is only visible has been around for many years and has even been portrayed in the media. A common portrayal that is seen in the media is a person in a wheelchair who is navigating life. An example of this is seen on the show named “Glee”, which has a character in a wheelchair who sings. On the show, they explained that the character has challenges because of his physical disability. However, the character had far more issues than his physical disability that the show did not discuss further.

Another aspect of disability that is portrayed in the media is how people feel about having a disability. Oftentimes, the main plot line of a film featuring a person with a disability revolves around the fact that they are unhappy with their life and wish they were “normal”. There are also moments in films where a character encounters other issues because of their disability such as dealing with a side effect due to their disability. Because of the complexity of their disability, the film continues to show the character negatively. The character is not happy with their situation and cannot accept the challenge that their disability brings.

The misconception that disabilities are only visible and that a person with a disability cannot accept their disability is far from the truth. Many people with disabilities have learned to adapt to their disability and whatever it may bring. Furthermore, there will be times when people may not know that a person with a disability has multiple disabilities. This requires the person with a disability to tell their friends and family about their invisible disability. This could be a very hard topic for some people to encounter. In this chapter, we explore ways in which a person can tell their family and friends about their disability.

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Be Specific

If you are ever in a situation where a person does not know about your invisible disability and what it brings, you may have to bring it up in a way they understand. Do not worry about sounding professional or using correct medical terms because your main purpose is for them to grasp and remember what you're saying. For example, you can state in common terms what your disability is. For instance, you might say, "I'm a wheelchair user, but I also have low vision in my left eye." Next, explain how your disability affects you. You can say something like "Because of my low vision, I am not able to see far distances." Lastly, you can explain to your family and friends how to help you. For example, you can explain to them that you may need help in certain areas. You might say "Because I am low vision, I need you to read the menu to me at a restaurant" or "Because I am low vision, I need you to describe things in terms that I can understand them, like describing specifically where someone is rather than saying 'over there.'" In the end, it's up to you what you want to say to others about how your disability affects you. You do not have to go into detail or tell people your life story, but these are ways to help people understand your disability and how to help you.

Be patient:

Now that you have told your family and friends about your disability, you may think that the work is over. However, it has just begun and will require you to have more patience. For people who are not used to being around others with disabilities, it may be hard for them to remember that you have more than one disability. There may be times when they forget, and you may have to explain your disability to them again. This can be a tedious and frustrating process. However, it's important that you stay patient, calm, and understanding. You can even ask your family and friends what they don't understand about your disability to help them in the future if they don't remember. Furthermore, when they seem to forget about your other disability, try not to become upset or make mean comments. Remember, it's a lot harder for someone to remember something if they are not living with it. Many people who are not living with a disability may find it harder to understand all the aspects of having a disability. This is your chance to advocate for yourself and others with disabilities. You are planting the seed into your family and friends' minds to better understand people with disabilities, so that the next time they encounter another person with a disability, they are more likely to understand.

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Be Open to New Questions:

Another aspect of telling your family and friends about your disability is being open to new questions. Your family and friends may have questions about your disability that may be new to you. However, this means they're one step closer to understanding your disability and how to help you. The first important step is to encourage your friends and family to ask questions about any doubts that they may have. At first, they may not want to ask any questions for fear of sounding silly or insensitive. However, you should encourage them to ask them anyway and assure them that there are no wrong questions. Remember that this is not a one-time thing. There will be many more questions along the way, so it is important to keep an open mind. For example, I'm a wheelchair user, and it is pretty obvious that I have a disability to any person. However, my friend who has low vision has a less obvious disability. When I first started hanging out with her, I often became nervous about asking questions because I was afraid of sounding dumb. However, she reassured me that all questions are welcome. This made me feel better, and I was able to understand her disability more. Now when I have a question I'm not afraid to ask her because I know she will be honest. If I never asked my friend questions about her disability, I would be lost on how to help her and who she is as a person. This has also helped us strengthen our friendship and understand each other better.



Image description: a group of 6 people smile and pose with one another, some holding up the peace sign with their hands and other hand gestures.

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This will take some adjustment for everyone.

Lastly, you may feel like after some time your family and friends should already be adjusted to the other aspects of your disability, but they may require time to process what they have learned about your disability. For some people, this may not be an easy concept to understand, so you need to show them grace as they process this. One way to help them understand the complexity of your disability is to show films, videos, or television shows of characters with disabilities. You can even show them the media with people who have a similar situation as you and explain to them how you and the character are similar. You can also use this moment to express how your disability makes you feel as a person. You can discuss some of the challenges that you have had to endure because of having more than one disability. It also does not have to be a one-time occurrence for you and your family to watch disability media. As you and your friends or family continue to navigate the aspects of your disability, watching disability media can always be an opportunity to continue having open dialogue with them.



Image description: two men smile as the one on the left crouches and holds up an electronic tablet as the wheelchair user

Conclusion

Having a disability is not always easy, but with the right support, anything is possible. This is why your family and friends must know about every aspect of your disability. And just like you are feeling nervous about telling them, they might feel nervous or unsure about how to handle the situation, so it is important to open the lines of communication. Furthermore, this is an important time for you to be your own advocate and continue to spread awareness about your disability. Never feel ashamed of having more than one disability and always remember this is a process that happens slowly.

CHAPTER THREE: DISABILITY DISCLOSURE AND KNOWLEDGE IN THE WORKPLACE

BY MARLON MOORE

Congratulations!

You've been hired, welcome to the job. I'm sure you're wondering what's next. Here are the details of the job. You will be paid five dollars an hour and your pay will increase based on your performance to our standards. You will be granted a 15-minute break if you work under six hours and a 30-minute break for six hours or more. You are required to be on the sales floor and/or carrying boxes to the stockroom that may weigh up to 50 pounds. If you are not able to perform the required duties or if you are late clocking in, you will be terminated.

Welcome to the team!

Knowing Your Rights as an Employee

Sub-Minimum Wage

You've just been hired, and you're headed home to tell everyone the good news about the job. You're excited to discuss with friends that you will be earning \$5 an hour. On the other hand, your friends share with you that they are earning \$8.25 an hour. However, they think it's odd, but they don't say anything, and you proceed to tell your mom the good news. The fact that your friends are earning more prompts you to ask your mom and research if you are being singled out. Although you were extremely excited to get a job and unaware of the federal minimum wage which is currently \$7.25 an hour, you were being discriminated against again. However, a sub-minimum wage allows employers to pay disabled employees below the state's mandated minimum wage. Many disabled employees across the nation are affected by this law which allows companies to overwork and undervalue disabled employees.

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Reasonable Accommodations

During your shift, you were told by the shift manager to quickly bring boxes that weighed about 50 pounds each to the front of the store. You informed the manager that you would not be able to carry the boxes due to your disability. Also, at the same time, you must tend to your medical needs related to your disability which requires you to be off the floor for up to 15 minutes which is separate from the allocated break time. However, the manager calls you into his office and proceeds to complete a write-up for not performing the tasks that you were instructed to carry out. The manager believes your medical needs are not imperative and believes instead that you are trying to waste extra time on the shift.

After the write-up, you are instructed to clean the counters and empty the trash bins. But you have forgotten the steps to emptying the trash and the task is done incorrectly. Therefore, you suggest attaching instructions to the trash bin with a clear large print to help you complete the task correctly. You also become overwhelmed with loud noises and large crowds, therefore, you ask management to allow you to work in the back stockroom. During presentations at staff meetings, you have expressed

many times that your hearing is not the best and have asked to sit in the front of the meeting with closed captioning enabled on all videos.

In these situations, employees need to know their rights as an employee with a disability. Under the Americans with Disabilities Act (ADA), employers are required to adhere to reasonable accommodation requests that will help employees perform work duties to the best of their ability. In the United States, the ADA and the Rehabilitation Act of 1973, were put in place to ensure protection for individuals with disabilities in the workplace. Under the ADA, it is against federal law to discriminate against qualified individuals solely because of their disability. This creates equity in the workplace by mandating equal opportunities to advance in a job field. As well as section 504 adds more protection for individuals with disabilities who receive federal Funding.

Disclosing Disabilities

When applying for a job, the application might ask if you have a disability and legally you do not have to disclose that information. As I mentioned previously, jobs have found many ways to indirectly ask about disabilities with different innuendos such as requiring

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applicants to be able to lift up to 50 pounds on the job. Once you are hired it is still your choice whether or not you choose to disclose your disability. Disability disclosure can be important to create an understanding of your disability and needs amongst staff to facilitate the appropriate accommodations for the job. Companies with inclusive policies may influence you to disclose your disability to ensure you receive accommodations, but if you prefer to showcase your skills and abilities before disclosing any disability to eliminate stigmas or biases employers or coworkers might have legally that decision is up to you.

On the other hand, anything that is shared between you and your employer is confidential. However, it is important to be mindful not to overshare information because of the risk of bias and discrimination. Creating a workspace for open communication allows employers to empathize and/or understand your lived experiences, and accommodation needs to identify and resolve discrimination when it happens. Disability disclosure is a way for you to be more comfortable as an employee and for those around you when everyone understands your disability and the accommodations you require.

Discrimination and How to Handle It

Laws and regulations that protect individuals with disabilities are in place, but discrimination persistently disrupts work experiences. Discrimination at the workplace can start right before you get the job. For instance, the employer can assume you cannot perform the job duties that are listed in the job description and could simply decline your application because of your disability. These are two examples of employment discrimination. This is important to be aware of so that you can identify and take the necessary actions to de-escalate a potentially hostile work environment. There are numerous ways to create a safe and inclusive work environment such as teaching employees the importance of diversity, inclusion, and equity. Furthermore, an employer cannot terminate your employment, demote you, or decrease your pay simply because of your disability. If you disclose your disability and a coworker or supervisor uses that information against you, then you can file a complaint through the U.S. Department of Labor. Promoting and understanding the accommodations as an employee with disability needs while eliminating stigmas and biases toward disabilities.

Conclusion

Lean into Your Strengths

As we approach the end of the chapter, I want to encourage you to use your strengths to advance in your career. Also, embrace and utilize your strengths and never allow the job to focus on your limitations. Showcasing your strengths as an employee allows the job, co-workers, and employer to consider the preconceived biases that are placed on you. As a result, employers will understand the importance of ensuring you have the accommodations needed to be the best employee. Ultimately, displaying your strengths at the job creates an environment where you are accepted as an important role you have on the team.

Overall, in this chapter, I hope you gained more knowledge and a better understanding of being a disabled employee and disclosing your disability in the workforce. Understanding the signs of discrimination in the job and application process is essential to combat biases and create reasonable accommodations for a more inclusive work environment.



Image description: A woman with limb loss utilizes her feet to paint. She is sitting in the grass with a park in the background.

CHAPTER FOUR: NAVIGATING PERSONAL RELATIONSHIPS WITH MORE THAN ONE DISABILITY

BY JESSIE ROGERS

Disclosing disabilities, and advocating for your needs in personal relationships is important, and so far, this book has been about disclosing your disabilities within your personal relationships. However, in personal experience, persons with disabilities tend to find one another and build friendships or professional relationships. On occasion, these relationships form outside of the control of the people involved; teachers or workplace authorities pairing students or co-workers with disabilities together on projects with or without their consent. However, no matter how the relationship is facilitated, it's still important to understand that both parties have a disability of some sort. Making those relationships last relies on not only being willing to advocate for yourself as you would in a relationship where you are the only person with a disability, but allowing the other person or persons to advocate for their own needs as well, and most importantly, working together to figure out how to build a relationship that navigates the combination of intersecting challenges you both bring to the table.

YouTuber Kaelynn Partlow, a therapist and speaker diagnosed with autism, released a short video talking about loneliness and Autism. Kaelynn says that the most disabling part of the diagnosis is loneliness. She goes on to explain that humans are highly social creatures, and having a brain that works differently complicates things. Furthermore, disability services only consider loneliness as an unfortunate side effect and not something that needs treatment. Kaelynn says that currently, services for people diagnosed with autism focus on



Image description: Kaelynn Partlow, a white woman with collarbone-length blonde hair and bangs smiles and looks towards the camera.

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with autism focus on independent living, life skills, and day-to-day care. While these are no doubt important, they do not teach social skills or give any guidance on how to happily coexist with other people in one's environment.

In personal experience, this lack of social skills isn't only relegated to services for people with autism. As a visually impaired person, I've witnessed this time and time again when visiting the state-run blind school in my state. I attended public school, and while it was isolating, I was given a range of social skills simply through observation. There is a marked difference in social skills when interacting with a student who attended the school for the blind for their entire educational career. Ultimately, this is another problem and should be addressed differently, however it's worth mentioning here. Going forward, I would love nothing more than to see social skills be added as a vital part of these services, however, we are still left with a generation or more that hasn't necessarily been taught how to be social, and who desperately need friends and interpersonal relationships, and this is where we see that people with disabilities tend to find one another and flock together.

So how exactly do you advocate for yourself in a relationship with multiple disabilities? How do you build a relationship where everyone involved is comfortable? The first step, in my experience, is acceptance. It might sound a bit on the nose, but I feel like it's super important to mention. When talking about the lack of social skills training above, I never meant that we need to teach these people to stifle the spark that makes them who they are, and I don't think that's what Kaelynn Partlow meant either. Embracing what makes you an individual is one of the hardest things to do, especially in our social media comparison-ridden society. However, it's one of the most freeing things you can do for yourself. Embrace your oddities and quirks, and make it fun. This chapter, however, isn't about self-love. Embrace your friends as they are just as much as you embrace yourself. I say this, fully realizing that it's easier said than done.

One of my very best friends has an autism diagnosis, and when we first met, I was incredibly taken aback by her extreme bluntness. She was never hurtful so to speak, but she said what was on her mind. I admittedly approached a bit timidly at first, because I was afraid she would be hurtful at some point. Now,

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her bluntness is one of my favorite things about her. It's the reason she says things that get us both laughing so hard our stomachs hurt and tears are streaming down our faces. It's also one of the reasons she is one of my best friends now because I'm an over-thinker with some pretty nasty anxiety. Who better to be friends with than someone who never holds back what she's thinking? This, of course, is an example of how our different quirks and disabilities intersect seamlessly without either of us having to advocate much at all.

My best example of our disabilities coming at odds, however, came several months into our friendship. This friend and I met in a church setting, and she learned to guide me around as a sighted guide rather quickly, because we would stay in the Sunday school classroom long after everyone else headed out, and she'd have to run me into the service while opening music was playing. In this setting, we're fine. It's a bit crowded, but even though our church is big, almost everyone we might encounter on the short trip from the Sunday school classroom to the sanctuary is aware, accepting, and welcoming of both of us. However, a few months into our friendship, I invited her to go to a storytelling event with me.

Our town is known for storytelling, and this particular night, we were going to go to the ghost story event that's part of one of the biggest festivals of the year. It was going to be crowded, and unlike our church, I knew that not everyone we encountered would be accepting and patient with us. I also knew that crowds are a bit of a problem spot for both of us. I called her before the event, and the conversation went something like this:

Me: "Hey. I know you've kind of guided me through a crowd before at church, but this is different. Are you sure you're okay with this? Okay with guiding me?"

Her: "Absolutely. Please know that crowds are a trigger point for me though, and I've been known to have panic attacks. Can you check in with me if I get quiet?"

That was it. It wasn't a difficulty, but it did require sacrifices for both of us. That's the thing with relationships where both parties have disabilities. It's important to learn to make sacrifices and compromises. Those things are important in any relationship with anyone you care about, of course, but it might look a little different. With this particular

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example, both my friend and I are comfortable enough with advocating both for ourselves and each other that we're pretty seamless most of the time. She trusted me enough to tell me where the trouble might happen, and I was happy to arm myself with the resources necessary to walk her through a panic attack should one arise. It didn't, and the ghost stories were great even if we got a bit damp from the rain that unfortunately fell on an outdoor event.

Ultimately, this is just one example, but most of the people I love have some sort of disability. Several are considering official autism diagnoses or have other neurodivergence, and some have physical disabilities.

Navigating a relationship with multiple disabilities is just as much of a personal thing as navigating any other relationship. The first rule in any relationship is to build what works, and there is no rule book or step-by-step guide for that. It is an individual thing, and if there was a rule book, the first rule would be to accept your people as they are. Disability or not, they are an individual first, and so are you. Don't kill the spark that makes you, or them, unique. It sounds cliché, but again I feel it's increasingly hard for everyone to embrace individuality in our media-driven society.

The next most important thing is not being afraid to advocate. This, of course, is what this whole book is about. You will have to communicate your needs in any relationship, but the other person will also need to do the same. Building that understanding between the two of you is so important. This, again, looks different for everyone, but I encourage you to learn that within personal relationships. Be willing to accept advocacy as well.



Image description: A Black woman wearing shorts, a pink/red top, an unzipped sweatshirt, glasses, and a mask walks on the sidewalk with a cane.

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Conclusion

Accepting advocacy takes a lot of work sometimes. It takes communication, and I don't feel like that is ever truly easy. Sometimes, you're going to have to have hard conversations with the people in your life, especially when it comes to navigating a relationship with multiple disabilities. You are going to have to find what works for you and the other person or persons involved, and that won't ever be set in stone from relationship to relationship. There are guides out there on good communication, and there are self-help books for just about everything, but in the case of navigating these kinds of relationships, nothing is more important than learning how to co-exist with your people as individuals.

CHAPTER FIVE: FINDING CREATIVE SOLUTIONS TO ACCESS NEEDS IN PERSONAL RELATIONSHIPS

BY ALEXIS SYE

Consider a group of friends who started a Zoom book club during the early days of the pandemic. They now want to move it in person so that they can take turns sharing their favorite snacks. There is only one small problem: Sarah is hard of hearing and speech-reads, and Matt is immunocompromised and needs to wear a N-95 mask to protect himself. How can the group meet both of these needs and ensure that everyone can meaningfully participate?

For many disabled people, situations like these occur and must be navigated every day. This chapter aims to demystify accessibility in personal relationships by providing a practical and positive mindset for approaching these situations, in addition to defining access needs and explaining how they can conflict.

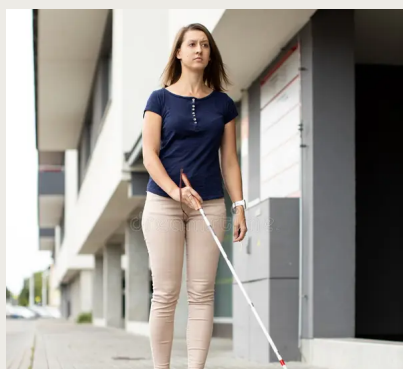


Image description: a white woman wearing a navy blouse and khaki pants walks outside a building with a guide cane extended out in front of her.

Access Needs and How They Can Conflict

An access need is anything that someone needs to communicate, learn, or take part in an activity. Everyone, disabled and non-disabled, has access needs, and no one person's needs are more important than another person's. An accommodation is a modification or alteration of rules, environments, or practices that allows someone's access needs to be met. Accommodations are similarly helpful for everyone, disabled or non-disabled. By framing access needs and accommodations as common to all people,, we remove some of the

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stigma associated with disabled people discussing their access needs. For example, everyone has the same need for communication in a language they can understand. If the President of the United States visits France but does not speak French, they would need the accommodation of an English–French translator because the French language is not accessible to them. Similarly, a d/Deaf individual may need an American Sign Language interpreter because spoken English is not accessible to them. Both of these examples detail an accommodation for an access need, yet one is more stigmatized than the other. This should not be the case! All access needs are equally valid and deserving of accommodation.

In some situations, the access needs of one person may conflict with the access needs of another, as we saw in the book club example with Sarah and Matt. Similar conflicts arise often in everyday life because each individual and their needs are unique. We must make sure that we are equipped to support all access needs rather than prioritizing one need over another. By accommodating all needs, we can create spaces that are inclusive to everyone and work towards a more integrated and accessible future.

Approaching Access Needs in Personal Relationships

Unlike in schools or the workplace, the Americans with Disabilities Act does not cover accommodations in someone's personal life and relationships. Thus, any accommodations must be paid for and organized by the disabled person and those around them, which can quickly become expensive and exhausting. In this section, we will discuss how to approach access needs in personal relationships, from having an open and creative mindset to finding concrete solutions.

The most important part of navigating access needs in personal relationships is having an understanding that access is created together. It is not solely the responsibility of the disabled person. Instead, access to personal relationships is the responsibility of all involved. Whether it be arranging a book club or planning a holiday party, all access needs should be accounted for, and all involved should help to create access.

In addition to thinking about access as a collective responsibility, access should be approached with an open, creative mind. Since the funds for ideal accommodations may be

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limited, more creative solutions may be necessary. This may include incorporating the latest free or low-cost assistive technology—like automated captioning on video conference platforms—or reliance on more old-fashioned solutions—like writing notes back and forth to communicate. Regardless of the specifics, the most important part is that everyone is working towards access for all. Solutions may not be perfect, but the effort is what will make disabled people feel like those in their lives truly want them in a space.

Revisiting the book club example with Sarah and Matt, there are several ways to approach these conflicting access needs, all of which include a collective and creative effort. Depending on the specifics of Sarah and Matt's needs, any number of these approaches could be successful.

Low Technology Solutions

- If Matt feels comfortable lowering his mask when he speaks, Sarah could still speech-read.
- Matt could write down or type what he says and show Sarah.
- Another person in the group could repeat Matt's answer so that Sarah can speech-read with that person.

Medium Technology Solutions

- If Sarah has hearing aids, Matt could speak into a microphone connected to Sarah's hearing aids to reduce the need to speech-read.

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High Technology Solutions

- The group could purchase a microphone to pass around and a speaker to amplify all voices. This equipment is also commonly available for rent or available to check out from a local library.
- Matt could speak into a speech-to-text software and show Sarah. There are several free or low-cost speech-to-text software available online. This may or may not require an external microphone for improved accuracy, depending on the software used and the internal microphone on the device running the software.
- The group could run a hybrid meeting so that Matt could be in a room alone without a mask on and allow Sarah to speech-read. Matt could join from his home or another room in the host's house so that he can also get the treats shared at the book club. Hybrid meetings typically require external microphones to ensure that the audio quality on the video call is good.
- To reduce the risk of COVID-19 transmission, all participants could also be required to take a rapid test before attending the book club. This is a smart choice in general, but it could also help Matt feel more comfortable removing his mask when speaking, which would facilitate solution number one.

Some of these solutions may work better than others, and the first solution likely tried will not be the best one. It may be awkward to wait for Matt to write his statements down or for someone to repeat what he says, but it will become more natural the more that the group does it. A little awkwardness is certainly better than making a space that Sarah or Matt does not feel welcome in. Some of these solutions could also be combined to improve the quality of the accommodations, and there are likely many solutions not listed here. This list merely illustrates the variety of solutions available across the technological spectrum that can be implemented without much monetary investment.

Conclusion

While the solutions discussed in Sarah and Matt's situation are far from universal, they provide a great example of what kinds of free and low-cost solutions can be creatively implemented to make all feel welcome and supported in spaces outside the jurisdiction of the Americans with Disabilities Act. Each of these solutions is also a collective effort that does not prioritize one person's needs over another or put the burden of accommodation on Sarah or Matt.

I would like to end with the idea that access and inclusion are a journey, not a destination. As Sarah and Matt's needs change, and as other people in the group's needs change, solutions that worked previously may stop being effective. At this point, new creative solutions will be called for, and the process of creating an accessible space should continue. This is not a failure or a setback; rather, it is an opportunity for the group to grow and change together. Every day, we have the choice to make things accessible or to allow the inaccessible status quo. Choosing access means working towards a world where people with disabilities truly belong in all spaces; choosing access means disability justice. Use this guidebook and all of the resources it contains to choose access every day.

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Supplemental Resources

Searchable Online Accommodation Resource (SOAR)

This is an online resource that is aimed towards helping people find accommodations that match their needs for the workplace, but it can also be a great way to start thinking creatively about access solutions in one's personal life as well.

"Revolutionizing Accessibility: 100 Low Tech Assistive Technology Solutions for Classrooms"

This article has the spirit of access in mind as it demystifies accessibility in the classroom. Similar solutions would be helpful in personal contexts as well.

"Guide to Disability Rights Law"

This government website details existing disability rights laws and can assist one in determining if a situation is covered by the ADA. *Note: the book club example used in this chapter will not be covered.*