Spring 2020

The Latest in
Disability
Research, Advocacy,
Policy, and Practice
RAPP
NEW HAMPSHIRE

THE INTERSECTION OF DISABILITY AND SEXUALITY

THEME OVERVIEW

Welcome to the newly renamed and redesigned Disability RAPP. The themes explored each issue, like this issues' focus on the intersection of disability and sexuality, inform us and empower us to break barriers and challenge traditional ideas of what it means to live with a disability. We updated the Disability RAPP design to be more accessible in both its print and digital formats.

We want to hear from you. Please share your ideas for future themes, or your suggestions of how we can increase accessibility, by emailing mail@drcnh.org.

Happily married! Jim Piet and Pat Vincent-Piet on their wedding day.

Finding Love with Common Ground

Two Perspectives. One Future. By Vanessa Blais

Jim Piet and his wife, Pat Vincent-Piet, had very different experiences growing up with Cerebral Palsy (CP). Their story is one of faith in themselves – and the undeniable laws of attraction.

"Pat and I grew up much differently, but we landed in the same place," shares Jim Piet. "I was in a segregated environment from the age of four because my own community did not have the ability to support a person like me in its public school. There were no services. Pat, on the other hand, grew up in an inclusive environment in public school."

Jim Piet spent his young life surrounded by professionals and peers with similar disabilities.

Pat Vincent-Piet did not realize the reality of her disability when she was young. She was never treated differently by her family, and never had any special accommodations at school or in her community. However, she knew that she was somehow different from her peers.

(continued on page 2)

A COLLABORATIVE EFFORT BY THE
Disability Rights Center-NH, UNH Institute on Disability, and NH Council on Developmental Disabilities

Finding Love with Common Ground *(continued from page 1)*

Once, when Jim and Pat were on a date, Jim jumped at a loud noise. Pat shared with Jim that she did the same thing. “I didn’t realize that my reflexes and physical quirks were associated with my Cerebral Palsy,” says Pat Vincent-Piet. “Jim became the first person I could talk to. I never had a close friend with a disability.”

When asked how Jim used to feel about the idea of having a relationship and a family he replied, “I had a speech therapist that had a similar disability. He could feed himself and drive his own car. He went to college and got married and had a family. I think he gave my parents hope that life with someone could be possible with the right support.”

Dating Life

Pat was in the process of going through the NH Leadership Series course when she met Jim, who was a presenter. She felt strongly that she needed to talk with him to get information about life with Cerebral Palsy. “I actually tracked him down,” Pat says. “I went to an expo where I knew he’d attend. There is something attractive about being around someone who has an understanding of your experience, and it didn’t hurt that he wasn’t bad looking! He was the first other adult with CP that I met who was living with quality of life on his own.”

Jim and Pat have had some unique dating experiences.

Jim recounts, “The first time we ate together alone she tried to use different utensils for herself and for me. It was too confusing and eventually she asked if it was ok to use the same fork. Now, we not only share our meal, we share our utensils.”

Bathroom mishaps seem to be a recurring theme. The couple tells of a visit to the Chunky’s movie theater men’s room where the accessible stall was not big enough for both of them. They ended up in the middle of the room next to the urinals. A man came in and began to relieve himself at the urinal next to them. They returned to the theater where a dramatic disaster movie called *Day After Tomorrow* was playing. “We were laughing hysterically when we walked into the theater,” laughs Pat. “I can only imagine what people were thinking.”

Then, there was the first time Pat stayed the night at Jim’s house. “I knew we were going on a date, but I didn’t know how far this date was going, so I didn’t inform my morning aide that she would be there,” Jim shares. “The aide walked into the bedroom and there was Pat”.

“Fortunately, she and I knew each other,” Pat laughs.

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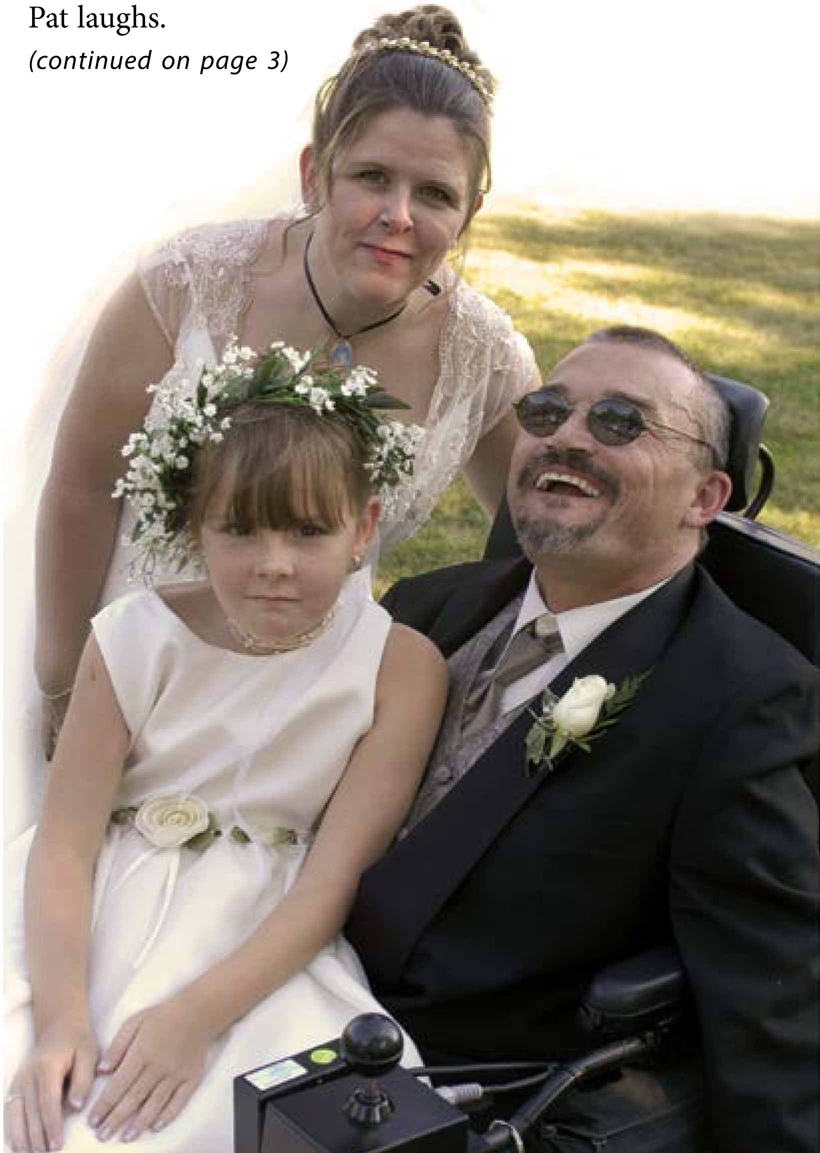
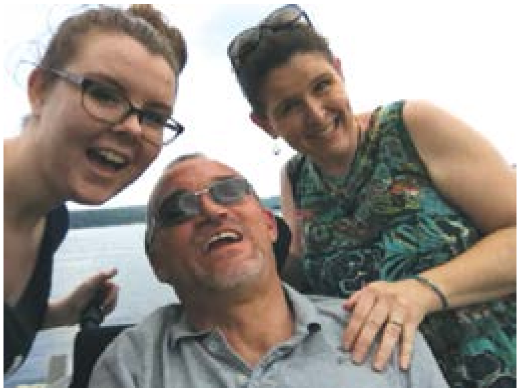


Jim, Pat, and Katelin celebrate together in 2004.



Life is full of shared experiences for the Piet family.

Celebrating Resilience

Pat's daughter, Katelin, was four years old when Pat began dating Jim. When asked what Katelin originally thought of Jim, Pat replies, "Jim was not what she had in mind. She asked me if we were going to get married very early on. I said, 'I don't know, maybe. Would that be ok?' She said, 'No, I want you to marry someone dashing!' She wanted me to marry my chiropractor."

Jim and Pat now agree that having two parents with disabilities makes Katelin a very independent person. "It makes you realize how capable children are," shares Pat.

Most people were very supportive of Pat and Jim getting married. Jim's grandmother was especially thrilled that Pat was marrying "Jimmy." Pat had an uncle that expressed concern that she was taking on a lot, but Pat brushed it off because she felt that he didn't understand. "Everyone who knew us well was supportive," Pat comments.

Jim's advice to parents who question whether a relationship will be a part of their child's future is to ask themselves what they would say to a child without a disability. He adds that becoming comfortable with your disability is very important. "If you are, people will sense it right away," Jim says. "Don't make it shine. Don't make it who you are. Just start a regular conversation. Let them know WHO you are as a person."

"Concentrate on the things you have in common," Jim relates. "Shared life experience is so important. If you believe you can have a connection with someone, then you can have a relationship."

"There is more and more representation out there showing people with disabilities in relationships," Pat adds. "You can find them on YouTube, TV shows, and movies. Seeing and hearing from those who have the same experiences – and have carved a life for themselves – is truly rewarding. People living with disabilities should be exposed to these wonderful stories of hope."

Vanessa A. C. Blais is a Project Manager with the NH Council on Developmental Disabilities.

Survey

What are the opportunities for, and barriers to, meaningful relationships? Take this 15-minute survey and tell us what you think!

Are friendships important to you? Take this survey!

The University of New Hampshire and Boston University Wheelock College are collaborating on a research study to improve our understanding of supporting and creating meaningful relationships among people with – and without – disabilities. If you would like to help us identify what works and what doesn't, visit:

http://bit.ly/2lHaQld.

Word and PDF versions are available at this link.

The Marriage Paradigm

Finding Love. Losing Eligibility.

By Stephanie Patrick

Over the past decade, marriage equality has become part of the common vernacular. Marriage is a choice for people of all races, genders, and sexual orientations. The only people routinely left out of this conversation are people with disabilities.

Living with a disability can be incredibly expensive. Many people with disabilities depend on Medicaid to access the services and supports they need every day to get dressed, eat, and take care of basic needs. These supports can cost thousands of dollars a month and are not typically covered by private insurance. Many people with disabilities who are unable to work rely on Supplemental Security Income (SSI), or Social Security Disability Income (SSDI), to cover their basic living expenses.

People with and without disabilities get married so they can formally profess their commitment to another person. People with disabilities should not be forced to contemplate divorce in order to obtain the healthcare that they need. However, marriage – or sometimes even a committed relationship – is off limits for many who depend on Medicaid, SSI, and SSDI because the joining together of income and resources can make a couple's income and assets too high for the person with a disability to remain eligible for the services they rely on.

In New Hampshire, when only one spouse of a married couple is applying for nursing home Medicaid or a Medicaid waiver, only the income of the applicant is counted. However, this is not the case for regular Medicaid, which many people with disabilities rely on, where the income of both spouses is included towards the income limit of the applicant. Only a few assets are exempt from the asset calculations that determine eligibility for programs used by people with disabilities; depending on the specific program, only a minimal amount of cash and personal property, a vehicle, or a home may be excluded. Additionally, many of the income and asset limits used in determining eligibility are prohibitively low as they have been in place since 1989, with few adjustments for inflation.

The right of people with disabilities to marry is undermined by current policies around eligibility. People with disabilities are being forced to remain single or divorce so that they can keep the services they rely on to live. As laws are implemented to ensure marriage equality for all, policy makers need to recognize that the current eligibility calculations for Medicaid and other programs are outdated and equate to a marriage penalty for people with disabilities.

Stephanie Patrick is the Executive Director of Disability Rights Center – New Hampshire

Policy makers must take action to end the marriage penalty for people with disabilities.

For more NH-specific information on this topic, visit:

medicaidplanningassistance.org/medicaid-eligibility-new-hampshire

dhhs.nh.gov/dfa/documents/fam-asst-fact-sheet.pdf

Knowledge is Power

Teaching Sexual Self-Advocacy

By Katherine McLaughlin, M.Ed.

According to the Bureau of Justice Statistics, National Crime Victimization Survey, Special Tabulation, and the National Public Radio series, *Abused and Betrayed*, people with Intellectual/Developmental Disabilities (I/DD) are seven times more likely to be sexual abused than those without.[1]

Here are steps to reduce this statistic:

- Believe we are all sexual beings – including people with I/DD – and that we all need sexuality education
- Provide age appropriate, medically accurate, sexuality education
- Provide positive messages – not fear-based language – about sexuality
- Empower individuals with I/DD to be sexual self-advocates
- Train individuals with I/DD to be sexuality educators
- Increase training opportunities for staff, caregivers, and self-advocates regarding individuals with I/DD and sexuality education

Sexuality education is the first line of defense for all people, but especially those with developmental disabilities. Even if you agree that sexuality education is important, there are many reasons why you might not want to talk about it:

- You may not know how to begin, or what topics to cover.
- You may know what to say, but don't know how old a person should be before you start the conversation.
- You may fear that talking about it will encourage sexual activity.
- You may not even know what you believe regarding sexuality.

But you can learn! In collaboration with Community Support Network Inc., the Developmental Disabilities Council, and Elevatus Training, there will soon be an all-day, Concord-based training for parents and professionals on how to address sexuality and sexual abuse prevention, and an all-day workshop for people with disabilities on *Becoming a Sexual Self-Advocate*. By providing accurate and practical educational materials and trainings we hope to elevate, educate, and navigate this topic. Many people have said that talking about sexuality was much easier than they thought it would be, and have gained confidence in this area with just a little support.

Statewide sexuality trainings are a powerful, proactive step towards empowering and educating individuals with I/DD, and helping to identify and prevent sexual abuse. Let's all work on helping people with I/DD lead healthy lives with positive and enriching relationships. Together, we can make a difference.

Katherine McLaughlin, M.Ed. trains individuals, staff, and parents on sexuality and developmental disabilities. ElevatusTraining.com

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[1] Bureau of Justice Statistics, National Crime Victimization Survey, Special Tabulation.

The Right to Sexual Relationships

By Stephanie Patrick

In a world where we classify, sort, separate, and stigmatize, it is important to remember that people with all types of disabilities are sexual beings, with the same diversity of sexual desires and interests as people without disabilities. The American Association on Intellectual and Developmental Disabilities puts it this way:

> *"People with intellectual disabilities and/or developmental disabilities, like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected."*

There is an ugly history of forced sterilization and other violations of the sexual and reproductive rights of people with disabilities. "Between 1918 and 1960, when the policy was abolished, 450 residents (of Laconia State School) were sterilized, three-fourths of which were women. For many years, sterilization was a requirement for a resident's release."[1] Though involuntary sterilization for people with disabilities is no longer commonplace, discussions about the sexual and reproductive rights of people with disabilities are also rare. This lack of information may lead to emotional and physical vulnerability, as well as misinformation and risky sexual behaviors.

It is critical that agencies and service providers promote healthy sexual relationships for the people with disabilities they serve. Service providers must train and support Direct Support Personnel (DSPs) to address sexuality and the sexual needs of the people they support. Sex education and family planning are critical elements of person-centered planning and, yet, they are often omitted.

Having a disability does not equate to a loss of sexuality.

Service providers and DSPs must recognize and understand how their own feelings about sexuality, reproductive justice, and sexual orientation are impacting the people they serve. "…there remains, for the vast majority of people with Intellectual/Developmental Disabilities (I/DD), a major area of deprivation and inequality, a lack of opportunity, choice, and the inherent right to develop and participate in social relationships which may involve sexual expression. The barrier lies not in the inability to develop responsible social and sexual behaviors, but in the misapprehensions and collective negative attitudes of some administrators, professionals, family members and the uninformed general public... The issue is over-control and a denial of basic human rights."[2] Service providers and DSPs must be trained to leave their personal biases at home so that they can support people with disabilities to make their own decisions while providing current, fact-based information around sexual health, contraception, and consent.

Service providers must also consider how their organizational policies and practices help promote or hinder healthy physical relationships. Restrictions on overnight visitors, lack of supports for dates, restrictions on alone time, or lack of privacy in discussions with healthcare professionals are all common policy-based barriers that people with disabilities face. People with disabilities must be allowed to determine

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[1] http://bit.ly/2TVFowh

[2] Ames, R. & Samowitz, P. (1999). Viewpoint [published by AAMR].

the types of physical relationships they want and then be given the supports to make these happen. Instead of policies and practices that prevent healthy relationships, policies should allow sexual relations between consenting adults in the privacy of a bedroom.

Discussions of sex and reproductive health can be uncomfortable, regardless of whether the discussion involves a person with a disability, but service providers and direct support staff must be trained to face these conversations directly. People with disabilities want relationships. Open lines of communication about sexuality and sexual relationships, including information related to same-sex relationships, are critical. Important topics to discuss include:

- Safe sex and reproductive health
- Consent
- Sexuality and sexual orientation
- How to define healthy relationships
- How to find healthy relationships

These discussions must be presented in a format that is accessible and appropriate to the person with the disability. This might mean using pictures or role play to facilitate the discussions. Without this knowledge, people with disabilities may not be able to recognize unhealthy or negative relationships in order to understand that they deserve better. Discussions of sexual topics must include opportunities for people with disabilities to ask questions and advocate for themselves in confidential spaces without fear of repercussions or stigma.

While family members, guardians, and service providers may help to facilitate these conversations, they can also be a barrier. Conversations with doctors about birth control, sexually tranmissable infections (STIs), and sexual health should be private unless the person with the disability requests support. The person with the disability should decide who to include in these conversations; discussions with the entire services team (case manager, provider, direct support worker, parents, etc.) without the okay of the person with disabilities are not acceptable.

Adults with disabilities are sexual beings with diverse needs, desires, and interests that must be respected and applauded. Family, agencies, and service providers must broach discussions of sexuality and reproductive health with a willingness to listen and openness to whatever they hear.

Stephanie Patrick is the Executive Director of Disability Rights Center – New Hampshire

Further resources:

arcwhatcom.org/wp/wp-content/uploads/2013/11/Healthy-Relationship-Workbook.pdf

mass.gov/files/documents/2016/07/va/hrhs-sexuality-and-disability-resource-guide-bw.pdf

STOP **This article contains sensitive material which may not be appropriate for all readers.**

Five Things You Should Know Before You Take a Crip to Bed

By Galen Spiegler

The sexuality of people who live with disabilities is exceptionally nuanced. In fact, there are entire books on the societal forces that push and pull on Crip sexuality. I am going to give you five pieces of advice to keep in mind when having an intimate relationship with a person living with a physical disability.

1. Create Time to Prepare

In today's sex culture, there is an idea, perpetrated by the media, that a person sees a sexy individual, grabs them, runs to a private place, and immediately has intercourse. This storyline is untrue for everyone, but especially for Crips. When a Crip wants to be sexually active, there is preparation that must happen in order for them to feel attractive and ready for intimacy. Often this preparation looks like a couple of minutes with a caregiver to clean up and prep in order to feel good in their body.

2. Great Crip Intimacy Makes its Own Schedule

After an aid leaves, the Crip and the lover have to get the room ready and get in bed. Crips have to make sure they have their chair in the right place and their pillows supporting them correctly. This process takes time; the lover who is not preparing the environment must patiently wait.

3. Crips are not Going to Break

In everyday life, Crips are touched gently and handled with careful precision. However, in the bedroom, that clinical touch can be replaced by firm physical contact. By giving Crips physical weight, they become anchored in the here and now, affirming they have a human body.

4. Pleasure is a Two-Way Street

One reason why people shy away from having sex with a Crip is that they are not sure that there will be pleasure equity. In reality, Crips can pleasure a partner as well – if not better – than a Temporarily Able-Bodied (TAB) person. Do not assume that just because someone lives with a disability, they are not able to please you physically.

5. Some Crips with Involuntary Movement Have an Advantage in Bed

The TAB sexual cycle is a linear process. However, the Crip sexual cycle is not nearly as predictable. This makes intimate relationships with people living with disabilities to be both exciting and rewarding.

Having an intimate relationship with a person with disabilities is an adventure in exploration, patience, and pleasure. Take the time to think differently!

Galen Spiegler holds a BA in Psychology from Wright State University. He is an author, ordained Marriage Officiant for Weddings on Rainbow Wheels and the Universal Life Church. He is the Founder and Director of Loungeability, and an intern at Thrive Tribe 419.

STOP **This article contains sensitive material which may not be appropriate for all readers.**

Brain Injury and Sexuality

By Beth A. Fisher, OTR/L

"Normal sex isn't a thing, so you don't need to know what normal sex is."
—Kathryn Ellis, OTR/L and Certified Sexuality Counselor

People with brain injury (along with other people with disabilities) are still sexual beings with sexual needs and desires. However, people with brain injuries may have difficulty in meeting their sexual and relational needs for a variety of physical, cognitive, and social reasons. Understanding the root of some of those problems is important in order to find solutions and to ultimately experience sexual fulfillment.

It is often said that the brain is the most important sexual organ. So then, it should come as no surprise that any injury to the brain will likely affect one's sexual functioning in some way. How a person is affected sexually after brain injury varies. Increased desire may also be coupled with impulsivity and may manifest as inappropriate remarks or repeated attempts to establish sexual relationships with unreciprocal partners. Decreased desire may be a result of the fatigue that often accompanies brain injury while the brain tries to repair damaged neural networks.

Additionally, physical changes such as hemiparesis (the inability to move parts of the body on one side), increased muscle tone, and impaired sensation can make intimacy uncomfortable, painful, difficult, or potentially dangerous. Communication and mobility challenges that often occur because of brain injury can impede social relationships, limiting a person's access to others they would consider as sexual partners. Hormonal changes (in addition to those caused directly by brain injury) are often a result of medications taken to combat the causes or secondary effects of brain injury such as high blood pressure or depression.

So, with all these negative sexual side effects as a result of brain injury, is there hope? Yes, there is! However, because the topic of sex is often taboo or not discussed, people may avoid talking about their experience with their sexual partners, their therapists, or their doctors. Partners can learn to let pleasure be the goal of sexual expression. Therapists can assist with scheduling a time for intimacy when the person is less fatigued. Doctors can adjust medications to reduce or eliminate some of the sexual side effects. Normal sex, though not a "real" thing, may be defined as the way a person had sex before brain injury, or how they perceive others to experience sexual pleasure. People with brain injury should know that sexual pleasure is different for everyone. In addition to the help people can receive from their counselors, therapists, and doctors, online forums such as the British site Enhance the UK (www.enhancetheuk.org) can provide information as well as the social support that a person with a brain injury may need to begin their journey to sexual satisfaction.

Beth A. Fisher, MS, OTR/L, CAPS
Fit to Garden Program Developer
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www.FitToGardenProgram.com

Making a Difference Through Advocacy

By Cynthia West

For Tammy Mills, it started with a public service announcement on domestic violence – and a Sheryll Woods novel with a sad backstory. It was all the impetus she needed to get the right information to the right people. As a member of the NH Council on Developmental Disabilities, Self-Advocacy Leadership Team, and People First of NH, Tammy was in a position to make a difference.

Tammy helped plan a training session on domestic and sexual violence for people with disabilities at the January 2020 People First of NH meeting. Twenty five participants – almost all of whom had firsthand or secondary experience with violence – participated.

Domestic and sexual violence has been taboo for way too long. Even now, there is a significant lack of data in New Hampshire on people with disabilities who have experienced abuse. It is imperative that the disability community is trained and knowledgeable about this very important issue. Collaboration between the disability community and the New Hampshire Coalition Against Domestic and Sexual Violence (the Coalition), along with the people served by its 13 crisis centers, is essential for the success of both communities.

"It is so important that we have discussions, role play, and feel open to asking questions about domestic violence," Tammy shares. "I'd like to open this training up to the general public – that's how important this topic has become."

Indeed, there was much to be learned. "While we conducted the training, a number of advocates with disabilities disclosed that they'd either experienced or witnessed violence in an intimate relationship in the past," shares Linda Douglas, Trauma Informed Services Specialist with the Coalition. "We need to make sure that advocates have information on what to do, and where to go for help."

The training session included helpful resources such as the Power & Control wheel created by Domestic Abuse Intervention Programs, Duluth, MN which highlights the undercurrents, as well as the obvious signs, of domestic violence. The Duluth Model's Equality wheel provides the opportunity to discuss positive, healthy elements of a strong, supportive, and equitable relationship.

As a result of topics that arose during this training, Marie Linebaugh, Program Director for the Coalition, will be presenting on Power and Control Dynamics with Caregivers at the Learn It! Live It! Love It! conference hosted by Advocate NH in Concord on September 25, 2020. This training will include guidance on navigating close personal relationships between people with disabilities and caregivers. Discussions will include identifying elements of healthy – and unhealthy – relationships, as well as what steps to take to get help if someone identifies that they are in a harmful situation.

Thanks to Tammy Mills, the People First training on domestic violence was a great success, and an exceptional opportunity for sincere and honest communication on an extremely difficult topic.

Crisis Help Line

How to Get Help

1-866-644-3574

There are 13 state-wide member programs that operate 24/7 crisis lines for survivors of sexual and domestic violence. The phone number listed above will put you through to a crisis center in your area.

IMPORTANT: You do not have to be physically injured to receive support from a crisis center. This line is meant to support people and provide resources. You can call even if you are not the direct victim of violence.

DISABILITY RIGHTS
CENTER - NH

DRC-NH is dedicated to eliminating barriers for people with disabilities across the state. Contact us to schedule a free consultation on a disability discrimination issue with an experienced attorney.

Know Your Rights: Issue Area Spotlights

Special Education & Parental Consent

Throughout the special education process, there are times when the school district must ask for your consent in writing. If you sign as agreeing, you are giving the school permission to move forward with what they have proposed. If you sign as not agreeing, the school will not be able to start the proposed action. **If you do not sign the document at all, the school can move forward as if you provided consent.** Learn more at drcnh.org/issue-areas/childrens-issues/education/special-education.

Celebrating 30 Years of the ADA

This July marks thirty years since the passage of the Americans with Disabilities Act (ADA). In our monthly e-newsletter we will highlight a different aspect of this fundamental civil rights legislation including transportation, voting, recreation, education, and much, much more. Signup for our e-newsletter at drcnh.org.

How Do I Report an Issue Relating to a Representative Payee or Beneficiary?

Through our Representative Payee program, we help ensure certain social security beneficiaries are protected from financial exploitation and other abuses, and ensure that funds are being used appropriately and in the best interest of the beneficiary. Report an issue relating to a beneficiary or representative payee at drcnh.org/report-a-rep-payee-issue.

NEW HAMPSHIRE COUNCIL ON DEVELOPMENTAL DISABILITIES

The Council is dedicated to dignity, full rights of citizenship, cultural diversity, equal opportunity, and full participation for all NH citizens with developmental disabilities.

NH Council On
Developmental Disabilities
2 ½ Beacon Street, Suite 10
Concord, NH 03301-4444

Make a Difference and Participate in Developing our Next State Plan

Every five years the Council develops a state plan to establish specific goals and objectives to address needs of people with developmental disabilities.

WE NEED YOU TO TELL US WHAT IS IMPORTANT!

Filling out this survey will help us identify areas the DD Council can focus on to reduce barriers and create opportunities for people with developmental disabilities living in New Hampshire.

HTTPS://WWW.SURVEYMONKEY.COM/R/558RKQV

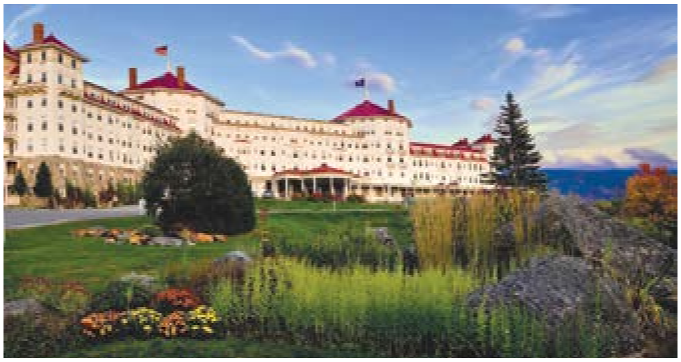
NEW HAMPSHIRE
Family Support
Conference

Look for The Hospitality Suite at the Annual Family Support Conference

Mr. Rich and the Youth Beatz performing at the Family Support Conference as part of the Youth Conference activities.

The NHCDD will once again be opening its Hospitality Suite in Room 119 at the beautiful Mt. Washington Hotel.

Whether you want to play a game, watch a movie, or just have a quiet space to relax and recharge, the Hospitality Suite will be open to all Family Support Conference attendees. Snacks and drinks will be available.



The Mt. Washington Omni Hotel, site of the annual Family Support Conference.

Connect with us:

Institute on Disability/UCED

University of
New Hampshire

The IOD promotes full access, equal opportunities, and participation for all persons by strengthening communities and advancing policy and systems change, promising practices, education, and research. Learn more about the IOD, our mission, and work at **iod.unh.edu**.

To mitigate the potential impact on the health and wellness of our community, many IOD events are being canceled, postponed, or held online. Please regularly check our events calendar for event-specific updates at **iod.unh.edu/events**.

nTIDE Lunch & Learn Webinar Series

First Friday of the Month | 12:00 pm EST

researchondisability.org/ntide

On the first Friday of every month, corresponding with the Bureau of Labor Statistics jobs report, the Employment Policy and Measurement Rehabilitation and Research Training Center offers a live webinar to share the latest data from the field of Disability Employment.

New England Regional Genetics Network Annual Meeting

April 16-17, 2020 | 9:00 am – 4:00 pm EST | Online

negenetics.org

This April, the New England Regional Genetics Network (NERGN) will host their Annual Meeting to share updates on research and projects taking place around the region and connect people to genetic services and opportunities for innovation.

New Hampshire Leadership Series

nhleadership.org

The NH Leadership Series has begun recruiting for the class of 2021. We want to be sure our class represents NH in all of its cultural, gender, ethnic, and geographic diversity. If you know someone who could benefit from this experience, please nominate them today.
iod.unh.edu/projects/nh-leadership/nominate

New Hampshire Leadership Annual Gala: To reduce the possible transmission of COVID-19, we have made the difficult decision to postpone our annual gala. To stay informed of future developments, please contact us at contact@nhleadership.org.

Fall 2020

2020 Assistive Technology Makers Fair

October 24, 2020
8:00am - 4:30pm EST
Durham, NH
$199 to attend
iod.unh.edu/atmakers

AT Makers Fair is designed to inspire participants to become creative problem solvers by bringing together makers of all abilities to share ideas, develop new skills, and enhance innovations for persons with disabilities. Novice to veteran makers of all ages and abilities are encouraged to register for this event.

Dating with Disabilities

It Just Takes Finding The Right Person

By Austyn Blais

Two of my earliest memories are running around the house in princess costumes, and stomping in the mud, despite my mother's disapproval. I grew up with a heavy dose of Disney™ magic and 80's Brat Pack sarcasm. I also grew up living with Spina Bifida and Hydrocephalus. I could recite my medical history by the time I hit middle school, and had a knack for forgetting about my scars until I saw them in the mirror. My family made it very clear to me from the beginning that my hopes and dreams didn't have to be any different than any other kid my age. As I got older, some of that wasn't totally accurate. This became abundantly clear when my friends started having crushes and dating.

Fun fact: When boys in your grade call you not-great names and make it known they do not like you as a person, they are equally as unlikely to like you as a prospective girlfriend. Who knew?! Dating as a teenager is tough. Dating as a teenager with a disability is the worst. I used to think the world was playing some weird prank on me. Anyone who did show an interest in me knew nothing about anything. Spina what? Wait…you have a hole in your back? We were off to a great start. I would go with the flow, and focus on school and friends instead of worrying about finding romance.

I was, and still am, willing to answer any questions people have about my disabilities. I respect when people are curious, and advocate for them to think of people in different ways. However, as I navigated dating in college – and later as an adult – I no longer found it necessary to start by explaining myself. We're all humans. Some of us just have a more extensive medical record than others.

Austyn and Mike share a relationship built on trust, respect, and understanding.

In terms of dating, I've had a few hits and misses – some terrible first dates and some even worse second dates. Because of my unique circumstances, I've had to navigate awkward conversations when it comes to being intimate, but aren't those conversations usually awkward at first? There's a lot of anxiety and preparation that can go into those moments – for safety and hygiene reasons – and there are not a lot of people into that.

As the years pass, I become more confident in what I want and don't want in a relationship. I care less about the physical shell of a person and more about the personality housed inside it. I like to think it's because I value when someone feels the same about me. I have a few scars, but my personality is solid. As my third grade teacher wrote on my report card, I am a joy to be around.

And yes, I ended up finding someone. He is one of the strongest and kindest people I know. I told him I liked him, and he told me he liked me back.

He would never, in a million years, dream of thinking anything differently of me, and he takes all of my embarrassing accidents and moments in stride. He makes me believe that maybe my family was right. You can have the same hopes and dreams as those who don't have disabilities. They just may take a little extra magic.

Austyn Blais is a mental health advocate and proud dog mom who works at SNHU in order to fund her love of travel.

Healing Through Relationships

By Karyn Harvey, Ph.D.

The good life is built with good relationships—Robert Waldinger

Life is hard. This is something we all know. Some of the things we go through can deeply affect us. An important question becomes, "How can we heal?" Different people heal in different ways, but there are a few factors that are the same for all of us. An important study conducted by Harvard University examined what made people happy over the course of their lives. Over 700 men were followed for almost 80 years, with one factor standing out above all others. Was it money, power, talent, skill? None of these – it was relationships.

People who had healthy, solid friendships and marriages were able to recover more easily from difficulties they'd faced earlier in life to become genuinely happy in their later years. Those who were isolated and had very few friends actually experienced more physical pain as they got older, lost their memories faster, and reported being less happy. Money, status, education, and talent had nothing to do with their happiness.

Christa is a woman who has been through difficult times. Both her parents died when she was young. She lived in an agency with four other people for a period of time, and then transitioned to living with just one other person. She was very lonely. Christa tried to make friends at work, but people were busy with their own lives and let her know as much. She started calling her Direct Support Professionals over and over again on her cell phone. Then, she'd call staff at the agency office repeatedly. People told her to stop calling so much. At her annual meeting, they talked about how she made too many calls, and even suggested addressing her calls with a behavior plan.

Further reading: http://bit.ly/39T5s0d

Then Christa met Derrick. It was a "get to know you" singles event. When Derrick and Christa sat down together, they both started talking and didn't stop for the rest of the night. Eight years later, they're still talking. Christa tells everyone she's found the love of her life.

When Christa's aunt died, everyone was worried. She was very close to her aunt, and she'd lost her parents so young. Would she be shattered by one more loss? She turned to Derrick and found the support she needed to gain strength in a way that no one expected.

Christa was able to find love and heal on many levels through having her own relationship. She'd watched day in and day out both the real and pretend relationships of others, but never had her own. Relationships are a human right. In some situations, people have to fight for that right and, in others, they happen naturally. Whatever way the healing happens – through friendships or relationships – no one deserves to live a life without them.

Karyn Harvey, Ph.D. is the Director of Training and Development at The Park Avenue Group in Baltimore, MD.

A singles event was the catalyst that changed the lives of Christa and Derrick.

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