



Repurposing Your Skills to Create Meaningful Change

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This will be an interactive session



We will tell our stories



We want to hear your stories



We want to find out what skills
you find most valuable and
why

First Challenge

- u What was your job before you became a caregiver, family member, advocate, or disability professional?
- u What skills did you have?
- u How did they translate in your current career or as a caregiver?
- u What about soft skills, which are equally--if not more--important?

Setting the Stage

Everyone's WHY is different



Everyone's lived experience is unique



We are all always growing and learning

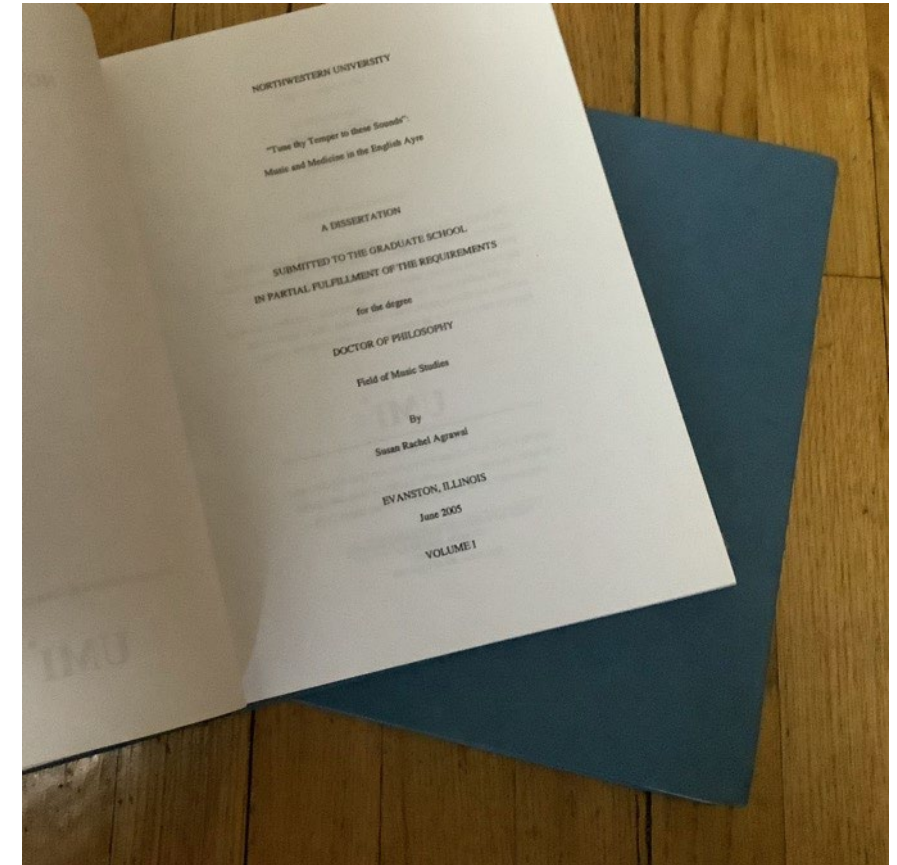


We all have
valuable skills!

MYRA'S REMARKABLE
SKILL IS...

Susan's story... once upon a time...

- u I was working on a PhD in musicology and theory with an emphasis on interdisciplinary humanities
- u My specialty was music and medicine in the 16th and 17th century
- u I was also an adjunct faculty at Northwestern University





And then Karuna was
born...

- u Karuna had multiple disabilities and medical conditions from birth
- u Her condition was degenerative, with multisystem organ failure over 8 years
- u I had to leave my job to care for her

Susan's Lived Experience

Early
Intervention

DSCC

IEPs, 504s,
special
education

MFTD
Waiver

Respite

Hospital
systems

All the
therapies

The birth of an advocate

- u In 2011-2, Illinois first tried to eliminate and then dramatically cut the Medically Fragile Technology Dependent Waiver
- u We spent almost three years advocating to save this program
- u I then worked in freelance advocacy for years
- u I now work for The Arc as Director of Family-to-Family



Kids belong at HOME!

Repurposing Susan's Skills

Skill	Before - Academic	Now - Advocacy
Writing	1000-page dissertation written in a year	OpEds, website content, fact sheets, letters to legislators
Research	Lots of reading, assimilating material, including in Latin and Italian, finding obscure texts	Reading bills, researching Medicaid, researching Waivers, reading Social Security code, finding obscure laws
Organizing People	Keeping 18-20yo students in line	Finding similar families and uniting us to fight for a cause in a Facebook group
Organizing Information	See the 1000-page dissertation above!	Boiling information down, explaining it in basic terms, and putting it on websites
Presenting Information	Submitting abstracts and getting papers accepted	Giving presentations and webinars to families and professionals

Lauren's story... once upon a time...

- u I was a litigator and federal law clerk
- u I always had a deep interest in social justice work





Nora presented the opportunity to combine my skills and my passion

- u Nora's first years of life were spent largely in hospital settings
- u I became curious about disability and disability rights
- u I decided to apply my skills in new ways

Lauren's Live d Experience

Ea rly
Inte rve ntio n

MFTD
Wa ive r

IEPs, 504s,
sp ec ia l
e d u c a t i o n

Me d i c a l
syste ms a n d
insura nce

The ra p i e s

Due Proce ss

Communi ty
Inte g r a t i o n

Lauren 2.0

- u Founded The Nora Project to bring disability studies to pre-K-12 classrooms and promote disability inclusion in schools
- u Did a TedX talk that has 65k+ views
- u Joined Equip for Equality's civil rights team as a community integration lawyer

Introducing The Nora Project's Standards for Inclusive Schools



Now available
to download!



Repurposing Lauren's Skills

Skill	Before	Now
Research	Conducting corporate investigations, researching causes of action for litigation	Digging into the details of the laws and rules surrounding education and community integration
Advocacy	Drafting and arguing motions, representing clients during depositions and at hearings and trials	Drafting appeals, complaints, pressing for systems change, arguing cases at hearings, creating content to engage the community, moving hearts and minds
Public Speaking	Presenting legal arguments, educating professionals regarding their legal rights and duties	 
Education/Technical Support	Creating materials for corporate clients to explain the law and improve compliance	Supporting the creation of new content for educators and students, creating "know your rights" materials, curating a speaker series for lawyers and advocates

Erica's story... once upon a time ...

- u Grew up with medically complex disabilities
- u Enjoyed life as an artist, musician, and traveler
- u Fell in love with Southern Illinois 15 years ago
- u 10-year career in Healthcare and Clinical Management/Admin.





And then these two
changed my world...

- u Margot and Cary share an ultra-rare disease resulting in multiple disabilities and medical conditions from birth
- u Their condition is considered degenerative, with an expected “limited life span”
- u I had to leave my job to care for them

The re-birth of an advocate

Passionate about storytelling, community building, caregiver education, and empowerment

Started a podcast and developed a social media platform, @Caffeinated_Caregivers

Worked as a professional information and outreach specialist at the Arc of Illinois and served on family advisory boards and councils

Developed a caregiver peer support program for families of medically complex children in Illinois at UIC Division of Specialized Care for Children



@caffeinated_caregivers

You and your caregiver bestie telling each other the most unhinged, dark jokes about how overwhelming life is



Caffeinated Caregivers



**Division of Specialized
Care for Children**



Erica's Live d Experience

Ho sp ita l
Syste m s

He a lthc a re &
Insura nce
Ad m in

Ea rly
Inte rve ntion

Divisio n of
Sp e c ia lize d
C a re fo r
Ch ild re n

MFID Wa ive r

Ho m e He a lth
Nu rsing

Ho m e bo und
Sp e c ia l
Ed uca tio n

Re purposing Erica 's Skills

Skill	Be fore	No w
Advocacy	Self-advocacy as a patient, then patient/family advocacy as a healthcare worker & admin.	Family leader: advocate for systems change, support families, and empower caregivers to use their voice.
Storytelling	Storying my life and disabilities in terms that non-disabled peers could understand.	Storytelling through social media, podcasting, and peer support. Sharing the collective voice of caregivers.
Connection	An inherent desire to connect and build authentic relationships personally and professionally.	Building community connection by creating safe spaces for caregivers to be seen, heard, and supported.
Diplomacy	Calm, fair, open, and steady-minded in the face of adversity and challenges.	Built trust with families and professionals, even in the most complex or emotionally charged situations.



We all
have
valuable
skills!

STEPHANIE'S REMARKABLE
SKILL IS PERSISTENCE!

Next Challenge

- u How are you using your skills now as a caregiver, advocate, or disability professional?

Skills	Before	After

What Gaps Do You See?

- u One of the most important techniques is to identify a gap and use your skills to help fill it
- u Identifying gaps often leads to meaningful change, both individually and systematically

What Steps Should You Take?

- u It's OK to completely start over - your skills will carry through!
- u Follow your passions and reassess your priorities
- u Reach out and ask questions
- u Use your networks

Who Should You Connect With?

- u Use ALL your connections from both past and present, from lived experience and career experience
- u Look for pre-existing training programs to get started

Thank you for joining us!

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