Is Guardianship the Only Option?

A Discussion about Guardianship and the Many Alternatives

Massachusetts DEVELOPMENTAL DISABILITIES Council
A Life of Opportunity

Council Staff

Jennifer Bertrand

MDDC

Deputy Director

Lee Larriu

MDDC

Training Manager

Massachusetts DEVELOPMENTAL DISABILITIES Council
A Life of Opportunity

Council/Community Panelists

Gyasi Burks-Abbott
MDDC Public Policy Committee Chairperson

Sandra Heller
Parent
MDDC Member At Large

Craig Kinney
Self-Advocate
Community Member

Consuelo Perez
Parent
MDDC Council Member

Tatiana Thomas
Self-advocate
MDDC Council Member

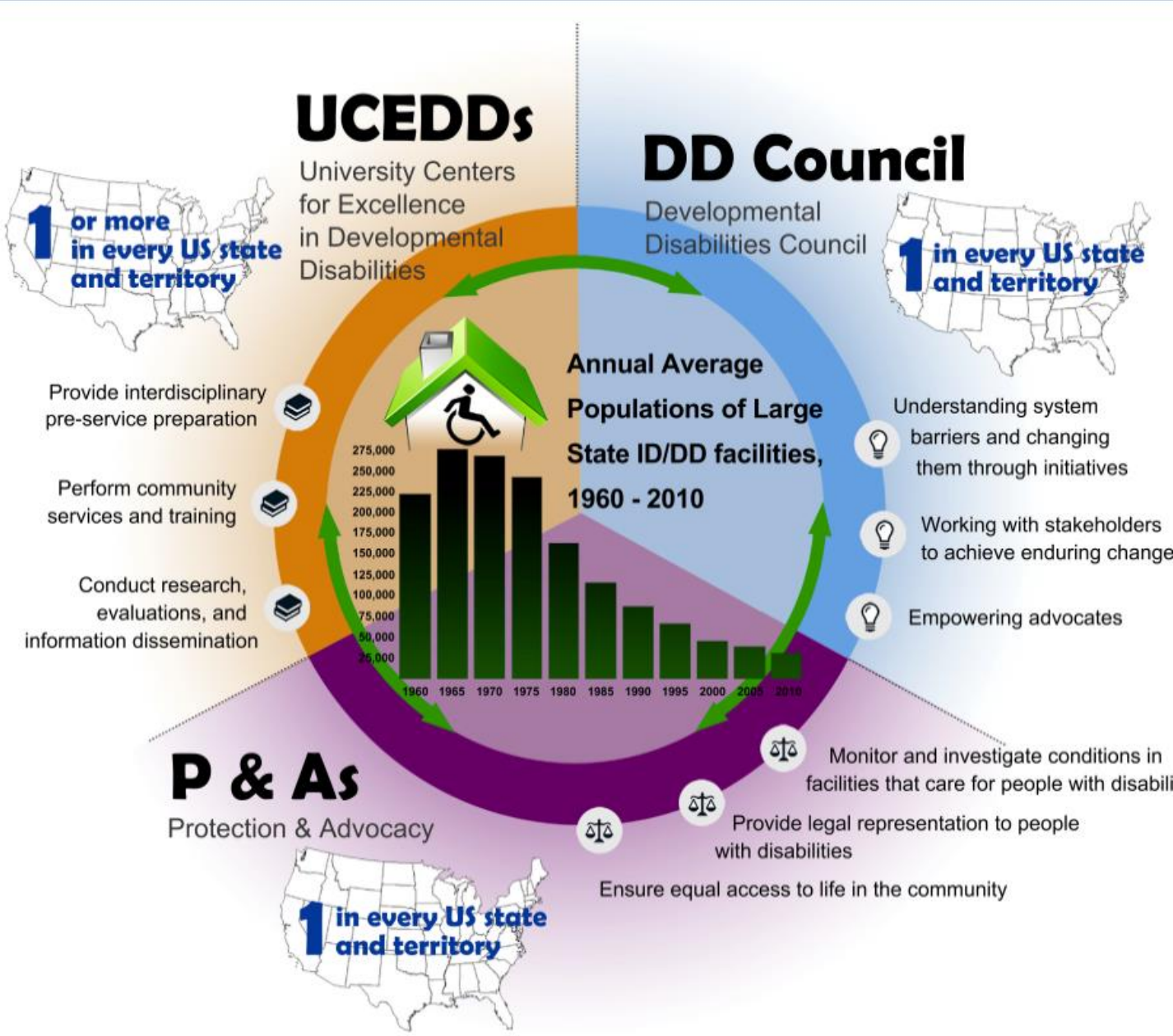
MDDC Mission

Our mission is to provide opportunities for individuals with developmental disabilities and families to enhance independence, productivity and inclusion.

Massachusetts DEVELOPMENTAL DISABILITIES Council
A Life of Opportunity

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)

- Establishment of state DD networks
- Federally funded DD programs in every state and territory - mandated with supporting people with DD and their families



Disability Law Center Staff

Hillary Dunn Stanisz

Senior Attorney

Laura Sousa Wagner

Staff Attorney

DLC Mission

The Disability Law Center (DLC) is the Protection and Advocacy (P&A) agency for Massachusetts. DLC is a private, non-profit organization responsible for providing protection and advocacy for the rights of Massachusetts residents with disabilities.

Our Mission: To provide legal advocacy on disability issues that promote the fundamental rights of all people with disabilities to participate fully and equally in the social and economic life of Massachusetts.

Agenda

- Decision-Making Issues
- Alternatives to Guardianship
- Panel: Personal Stories
- Guardianship
- Q&A

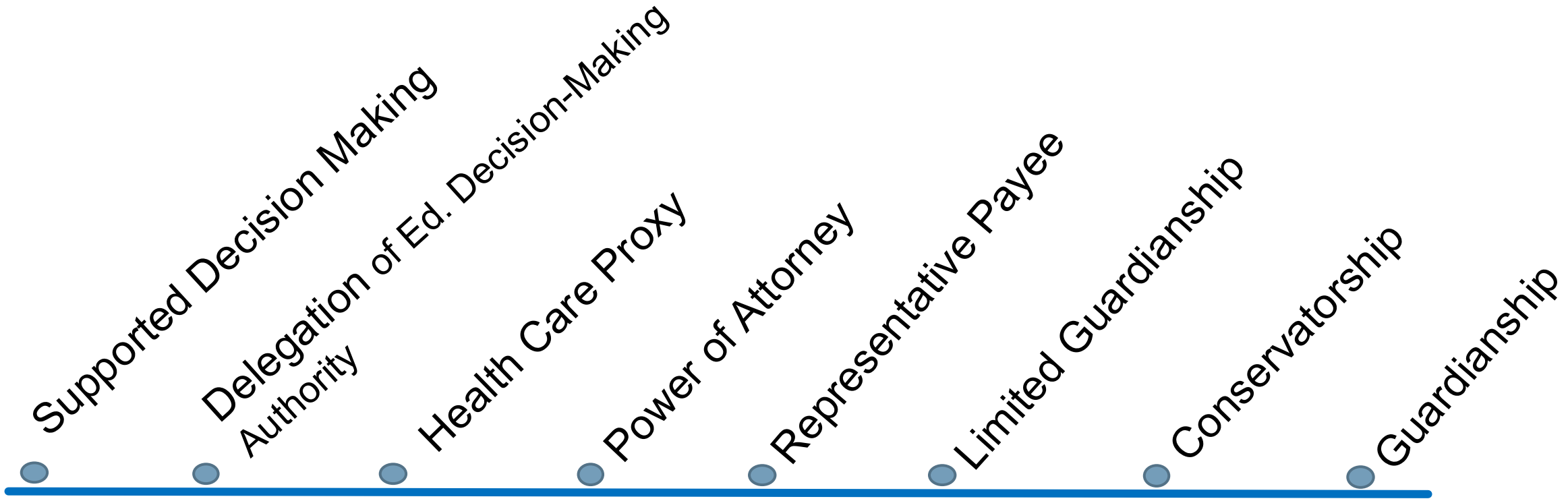
Age 18 and Beyond

- Presumption of competence
- Decision-Making: Independent? With supports? By parents or others?

Major Life Decisions

- Education
- Health Care/Medical
- Legal
- Financial
- Employment
- Housing
- Adult Services and Providers

When Assistance with Decision-Making is Necessary



The “Negatives” of Guardianship

- Impact on self-determination
- Court
- Responsibilities placed on guardian
- MA law: less restrictive alternatives; limited guardianship

Educational Decision-Making Authority

- Retain decision-making authority
- Share decision-making authority
- Delegate decision-making authority

Health Care Proxy

- Adult appoints a trusted person (Agent)
- Agent has authority to make medical decisions *if the adult becomes incapacitated*
- Can be completed without involving the Court
- Capacity
- Revocable

Power of Attorney

- Adult appoints a trusted person
- Appointed person manages and protects money, property, business affairs
- Can be completed without involving the Court
- Capacity
- Revocable

Representative Payee

- Appointed through SSA when the beneficiary is unable to manage their benefit checks (SSI, SSDI)
- Does not manage all of the beneficiary's finances

Supported Decision-Making

- Supported vs. Substituted
- Remain the decision-maker
- Choose supporters to provide decision-making help when needed
- Promotes self-advocacy, self-determination, independence

Supported Decision-Making:
What's happening in the U.S.?

- Cases
  - NY case (2012) - court recognized the use of SDM rather than guardian's substituted decision making. Terminated guardianship in favor of SDM model
  - Jenny Hatch (2013) – first US case to order the use of SDM as an alternative to plenary guardianship
- Legislation
  - At least 40 states have laws providing legal recognition of SDM, with some passing legislation requiring courts to consider SDM before guardianship.
- National Support
  - National Guardianship Association
  - The Arc of the US
  - American Bar Association

Supported Decision-Making:
What's happening in Massachusetts?

- 2014 Pilot
- MASDMC
- MA legislation
  - 2025 – bills reintroduced into MA legislature to establish legal framework for SDM
    - Allow individuals to enter into SDM agreements with trusted person while providing safeguards against abuse
    - Require courts consider SDM before establishing guardianship
    - Require all individuals who are turning 18 and at risk of being placed under guardianship be made aware of SDM as an option at IEP meetings

Supported Decision-Making:
Resources

- National Resource Center for SDM: https://supporteddecisionmaking.org/
- CPR resources: https://supporteddecisions.org
- MA Advocates Standing Strong: https://wearemass.org/supported-decision-making

Craig Kinney

MDDC – Alternatives to Guardianship

Supported Decision-Making

Help me understand. Let me decide.

I make my own decisions—with support I choose

Hi, I’m Craig Kinney. I’m 39, I have Down syndrome, and I live in my own home with a roommate. My supporters are people I know and trust. They help me understand choices—but I decide.

Support has always been part of how I choose

I started using supported decision-making as a teenager—before we had a name for it. A good supporter gives me real choices, uses clear words, helps me stay calm, and respects what I want. My family and supporters work with me, not for me.

Context: U.S. Administration for Community Living — support is tailored to the person, who keeps control.

I drive my own life—everyday choices count

I choose where I travel, what activities I do, and how I spend my money. My supporters help me compare options. The choice is mine. Sometimes a choice does not work out—and I learn and try again.

Hard decisions need more support—not less voice

Medical decisions were hard. I had a tracheostomy for five years and many surgeries. Medical words could be confusing, stress made it harder, and sometimes I could not speak. My supporters slowed things down, explained again, and listened to how I communicated. Sometimes I needed to hear it in my mom's voice. I made the final choice.

I decide who supports me in health care

I have a health care proxy and a power of attorney.

I have given my supporters consent to speak with medical providers and other professionals on my behalf.

They help make sure I am heard and understood.

Capability and support belong together

I am capable.

I may need help understanding.

Help me decide—do not decide for me.

Supported decision-making helps me live the life I want.

Learn more: acl.gov/programs/consumer-control/supported-decision-making-program • autisticadvocacy.org/actioncenter/issues/choices/sdm/

Support changes the process—not who decides

- Craig chooses supporters he knows and trusts
- Supporters help him understand options
- Supporters help communicate his choices
- Craig decides where and how he lives
- Craig decides who he spends time with
- Craig decides how he uses his money
- Craig decides about his health care
- Support changes by decision and over time
- Craig keeps his rights and final authority
- Source: U.S. Administration for Community Living

"I can make my own decisions with help understanding."

Craig R. Kinney
Proud Decision Maker

Gyasi Burks-Abbott

MDDC * Alternatives to Guardianship

Power of Attorney

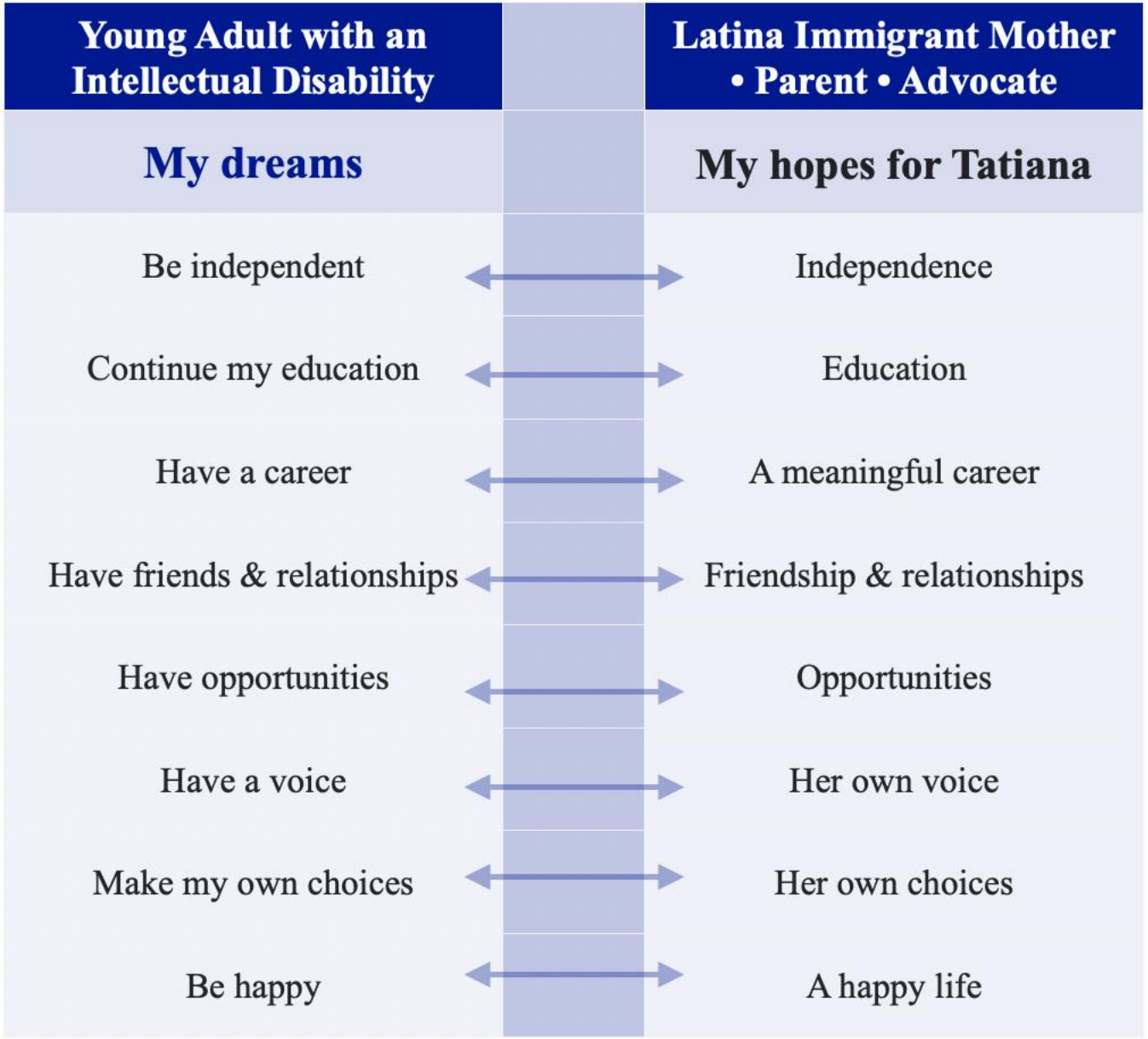
- I wasn't diagnosed Autistic until 17 even though developmental delays were noted since infancy.
- My mother got me on SSI and into a high school diploma program at a local community college.
- She remained my major decision maker and the person whose advice I trusted the most.

Power of Attorney (Cont.)

- When I turned 18, my mom considered guardianship but chose Power of Attorney instead.
- The best of both worlds: an advocate when I needed it and ownership of my own life.
- The way my mom used Power of Attorney helped me develop decision-making skills.

Tatiana & Consuelo

MDDC • Alternatives to Guardianship

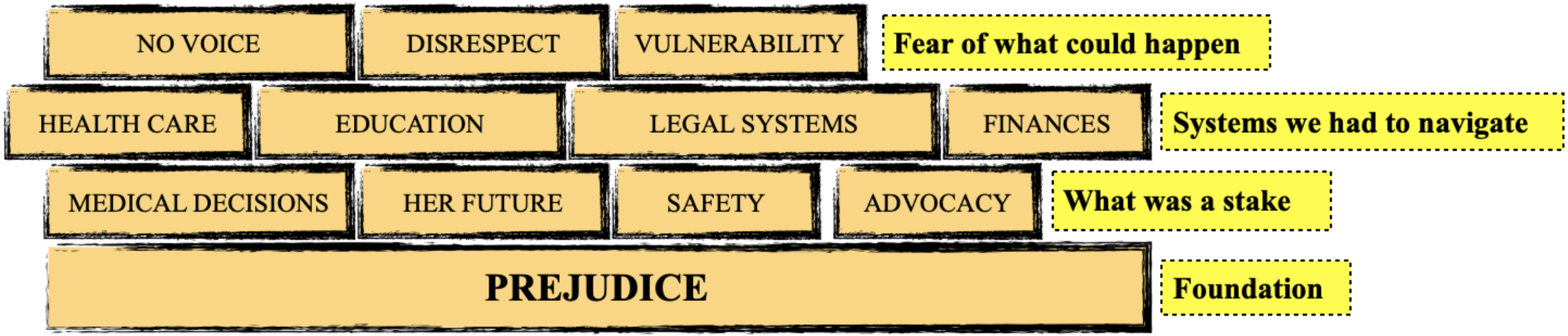


Her dreams and my hopes
are not the conflict.

The question is not WHAT Tatiana wants.
It is
HOW we support her in getting there

Why We Chose Guardianship

"At that time, guardianship felt like protection."



Protection should never become A GOLDEN CAGE .

“Whatever legal arrangement was in place, our goal as a family remained the same:”:

Tatiana needed opportunities

- ✓ **To try,**
- ✓ **To make choices,**
- ✓ **To make mistakes,**
- ✓ **To learn,**
- ✓ **and to try again.**

It is not simply about reaching the destination. It is about learning how to get there.

Guardian on Paper. My Voice in Practice.

My decisions start with me.

- Sometimes I understand right away.
- Sometimes I need more time.
- Sometimes I need things explained in a different way.
- And sometimes I make mistakes.

But I still need the opportunity to try.

Mistakes are part of learning.

Sometimes life gives us lemons...

What is the Guardianship Appointment Standard?

- Person has a **clinically diagnosed** condition that results in an **inability to receive and evaluate information or to make or communicate decisions** to such an extent that the individual **lacks the ability to meet essential requirements for physical health, safety, or self-care** even with appropriate technological assistance.

- Less restrictive alternatives are not enough

MA Law: Guardianships Should Be Narrowly Tailored

- Individual should keep as many rights/responsibilities as possible
- Assessment of functional abilities/limitations
- Medical Certificate or Clinical Team Report

Clinical Team Report

- Intellectual Disability
- Must be completed by a physician, a licensed psychologist, and a social worker
- Must be dated within 180 days of filing the guardianship petition

Medical Certificate

- Must be dated within 30 days of filing the petition
- Must be dated and examination must occur within 30 days prior to the hearing.
- Must be completed by a physician, a licensed psychologist, a certified psychiatric nurse clinical specialist, or a nurse practitioner

Role of the Guardian

- Make decisions pertaining to support, education, health and safety
- Encourage the individual to participate in decisions
- Consider the individual's expressed preferences/desires
- Act in the individual's best interest
- Exercise only the necessary amount of control/authority

Reporting Responsibilities

- 60 days from the appointment of the guardian
- Annually
- When the individual’s condition has changed

Protections for the Individual Subject to Guardianship

- Least restrictive – limited
- Right to an attorney
- Right to be present at the hearing

Important Limitations of the Guardian's Authority

- **"Extraordinary" medical treatment****
- Mental health facility

Extraordinary Treatment

- Examples:
  - Treatment with antipsychotic medication (Rogers)**
  - Sterilization
  - Abortion

Substituted Judgment

- Judge considers the following factors:
  - Individual’s expressed preference regarding the treatment/action
  - Individual’s religious beliefs
  - Side effects
  - Prognosis with and without the proposed action
  - Impact on the individual's family

Common Issues

- Guardianship/Alternatives Timeline
- PCA and AFC

Resources

- DLC handout: https://www.dlc-ma.org/wp-content/uploads/2023/11/Alternatives-to-Guardianship-and-Guardianship.pdf
- MA Probate Court forms: https://www.mass.gov/lists/probate-family-court-forms-for-guardianship-and-conservatorship
- List of Possible Limitations to guardianship: https://www.mass.gov/info-details/limitations-to-guardianship-and-conservatorship-for-clinicians-mpc-903a

Questions & Answers

Thank you!