Maximizing Legal Capacity: The Challenge for Families

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A Personal Perspective.

How to accompany and respect the building of self-determination in decision making: for my own son and for others.
You Will Learn About Me

✓ As a mom

✓ As a person: my values and commitment

✓ What I do with other families

✓ Understanding and learning through a personal journey with my son and with families around the world

✓ Mobilizing change

When I support decisions, my questions have to do with:

• Who I am
  • My Values
  • My Beliefs

• My own stories pertaining to “disability”

• My personal growth with Julián. Changing of situations
  • Educate for obedience – Self determination
  • Protection – Autonomy
  • Family makes decisions – Person Directed Planning
  • Child-adolescent-young adult-adult
  • Deciding for- To deciding with Decision making and it’s implications
  • Segregation- Inclusion in the community
BUT

I need to include the other:
• Who the person is
  - Their values
  - Their beliefs
  - Their culture, religion, country etc..
• His/her own story regarding “disability”
• What they want? What they need?

The Decision is theirs.

What do families have in common?

Every family worldwide has a common worry that dictates the decisions and choices made each day, which is...

What will happen to my son/daughter with an intellectual disability when I am not around?

I am not an exception!
As Families:

We are asked

- To support our sons and daughters with intellectual disabilities to have voice and control in their lives.

- Have the skills and tools to understand how to support our sons and daughters to make their own decisions.

- Required (as a result of legal practices and/or a lack of community awareness) to assume formal decision-making roles.

As Families:

Concerned

- About the safety of our sons and daughters in communities that have not demonstrated acceptance and inclusion.

- Blamed if our son or daughter makes a poor decision or a mistake.
Obstacles

- For many, particularly those with more significant support needs and those living in countries with few resources and services, their families are the ones that facilitate their inclusion in the community and the expression of their wishes.

- Families assume decision making roles.

- Many times it is their voice and concerns that frame the decisions that are made.

These factors have contributed to an over-reliance on families to be decision-makers and the notion that substituted decisions provide them with a form of protection.
Paradigm Change

**SO we need to start**
- Believing that our sons and daughter are valued people; have a voice and are able to express their own decisions.

**UNDERSTAND**
- Adults who are not allowed to make their own decisions are more vulnerable.
- To ensure a safe and secure future, people with intellectual disabilities need to be supported to make their own decisions.
- Guardianship and substitute decision-making are not the answer.
Accompanying Julián in his decisions helps recognize...

- He has a voice, opinions and goals
- The problems we discuss become more complex as he grows
- The risks are higher and we see them differently
- Our goals and dreams might be similar, but actually making them happen we often have different opinions
- **Reality** is a more complex road than **theory**
- Decisions are for Julián’s life
- Each decision affects my family and I differently than it does with my other kids because of Julián’s vulnerability and need for support.

Julian as a valued and included person in the community is the best place for him
Using Person Directed Planning

• I try to answer how he can participate in the life of the community being valued as a contributing friend and citizen as others of his same age.

• I try answering the following questions:
  - What does Julian wants and needs
  - How to support his choices and control over his own life
  - How to support friendships and membership in communities
  - How to support building skills and capacity
  - How to improve the way others recognize him as a valued member

For Julián

I support him with:

- Participation in the Community
- Develop autonomy
- Choice
- Be included
- Contribute
- Share common places
- Be respected
- Promoting recognized roles
- Presence in the Community
- Developing Capacities
Julián and Me:

He
• has a voice.
• needs opportunities to be consulted and listened to.

I
• Need to understand Julian's dreams and goals.
• Support Julian to act with his own voice.
• To let him grow and learn from his decisions

PROVIDING SUPPORT

Working together to find the best solution/option.

There are difficulties along the way, such as...
• Power imbalance
• Different information
• Different views
• Decisions impact our lives differently
• Warranty inclusion is a complex task.
It is a matter of Balance and Equilibrium

- Julian as a person
- Skills and Strengths
- Wishes and Dreams
- Possibilities
- Need of Support
- Safeguards
- Vulnerability (being taken advantage of)
- My fears
- Risks
- My beliefs and values
- Each one has a responsibility

What can we do as families?

- Learn more about how people are supported to make their own decisions
- Encourage our sons and daughters to develop decision-making skills as they grow and develop
- Provide information in plain language and help identify implications/consequences of decisions
- Expect our sons and daughters to have opinions
- Rely on behaviours and other forms of communication as an expression of will and intent and use that to guide decision-making
- Acknowledge that mistakes will happen and that we all learn from making mistakes
- Commit to supported decision-making
- Establish a support network/circle
- Reject pressure to seek guardianship orders
- Consult with others to guide the decisions