

SUPPORTED DECISION MAKING



CQL | The Council on
Quality and Leadership

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Who we are.....

- **International not-for-profit organization dedicated to the definition, measurement and improvement of personal quality of life for people with disabilities, people with mental illness and older adults**

- **Vision** – A world of dignity, opportunity and community for all people
- **Mission** – CQL is dedicated to the definition, measurement and improvement of personal quality of life for people receiving human services and supports.

What decisions have you made in the past 12 months?

- Accepted a job offer
- Chosen a new roommate, new home
- Bought a new TV, car, bedroom furniture
- Started taking a new medication/started treatment
- Chosen a different bank



When Making A Decision

How did you go about it?

- Talk to a trusted friend or family member
- Made a list of pros and cons with a trusted person
- Get more information about your options
- Get advice from a professional or expert
- Talk to someone who has more experience than you



SUPPORTED DECISION MAKING



- If you have done one or more of those things you have had supports to make a decision
- Rarely does anyone make a decision completely alone—most of us have informal supports and some of us have formal supports

What is it?

Supported Decision Making (SDM) is:

- A process in which people with intellectual or developmental disabilities (I/DD) make their own choices and express preferences with the assistance of a trusted family member or other person
- A tool to be used to help people with I/DD exercise the right to self-determination
- A method to empower people with I/DD to make their own decisions rather than simply appointing someone else to make decisions for them
- A way for people with I/DD to make legally enforceable decisions

Why is it important?

The opportunity and support to make decisions is important for persons with intellectual disabilities for a number of reasons:

- It helps us develop a sense of control over our own lives;
- It teaches us that we are responsible for ourselves and that we often have a responsibility to others;
- It helps us become more assertive and therefore, less vulnerable to exploitation; and,
- It helps us develop positive and healthy relationships with others.

Why is it important?

When people are supported to make decisions for themselves, they are seen as more capable by others.

When we are not allowed to make our own decisions or when someone else makes our decisions for us, we are seen as less capable and as having less value in our community.

Why is it important?

People with an intellectual disability say:

- We want to have our voice heard and acknowledged
- We want to be accepted for who we are
- We want to make our own decisions
- We want to be asked for our view and opinion on things
- We want to be treated the same as other people
- We want to have the same rights and opportunity to do things, with support only when needed

Independent but not Alone 2014

When someone with an ID or DD is not able to make decisions independently, the option is:

GUARDIANSHIP

Full or Limited

WHAT ARE THE DIFFERENCES?

Supported Decision Making

- Engages people in the decision making process
- Empowers people

Guardianship

- Gives someone else responsibility for decision making
- Stigmatizes and undermines the person's human dignity

People have been traditionally denied rights due to:

- Preconceived ideas
- Myths and prejudice about capacity
- Limited networks
- Communication



Why?

- Prompted in part by the new United Nations Convention on the Rights of Persons with Disabilities
- And an increasing demand by people with disabilities, families and supporters to recognize and promote rights and fair treatment
- There are efforts to use SDM to replace guardianship or at the very least to supplement it



CRPD Article 12

The Convention on the Rights of Persons with Disabilities

- Presume Competence
- Support people with “appropriate measures” to exercise their legal capacity
- Safeguards relating to the exercise of legal capacity
 - Will respect the person’s rights and preferences
 - Are free of conflict of interest and undue influence
 - Are proportional and tailored to the person’s circumstances
 - Apply for the shortest time possible
 - Subject to regular review by a competent, independent and impartial authority or judicial body



Jenny Hatch

Supported Decision Making Is Really Happening



Jenny Hatch

- In August 2013 in Virginia, Jenny Hatch won a lawsuit that gave her the opportunity to choose the life she wants.
- Jenny, a 29 year old woman with Down's Syndrome wanted to live with her friends, Kelly and Jim and work in the thrift store they own and run.
- Her mother and stepfather wanted Jenny to live in a group home
- The Judge had to consider two questions:
 - Was Jenny an incapacitated adult in need of a guardian?
 - Who would best serve in that role?

Jenny Hatch

SUCCESS!

The Judge said that Jenny needed a guardian to help her make decisions AND the guardian must take into account her preferences.



The Judge designated the people Jenny chose to be her supporters to be guardians for a limited time while Jenny gained experience in making decisions through Supported Decision-Making.

People have the right to contest guardianship

- Remove guardianship
- Reduce guardianship
- Change guardian

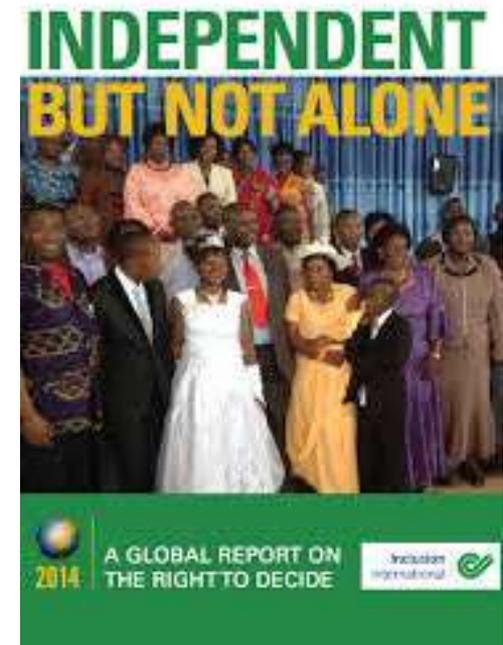
What's happening around the world?

INDEPENDENT BUT NOT ALONE 2014

This is a global report conducted by Inclusion International on the right to decide. This study took 2 years.

They spoke with 600 self-advocates, families, advocates and professionals.

Meeting with 80 organizations in 40 countries.



What is happening around the world?

- **New Zealand** - IHC in New Zealand is engaging in a layered educative program of work with families, disability support providers, legal professionals and community organizations to encourage an increased understanding of human rights obligations that support decision making and facilitate best practice innovations based on common sense approaches. Families have shown a great need for accessible, reliable and relevant information and to have discussions about advocacy issues impacting on their lives.

What is happening around the world?

India – Projects are happening nationally. It has become clear how important it is that the person is seen as a person and treated with respect, in order for the person to be seen as a decision maker.

Colombia, Argentina, Ecuador - Promoting individual self-advocacy; raising awareness with people with intellectual disabilities about their rights; involving people with intellectual disabilities in the organizations' governing bodies; and, increasing participation in political and civic engagement.

What's happening around the world?

Czech Republic - In the Czech Republic, Inclusion Czech Republic and Quality in Practice (QUIP) are working together to pilot a method to build circles of support and provide support in decision making for people with intellectual disabilities living with their families or in institutions. A new legislation on legal capacity abolished plenary guardianship. While partial guardianship is still included in the new legislation, new models have been included. However, no efforts have been made to prepare for the introduction of these new models.

What's happening around the world?

Lebanon - The Lebanese Association for Self Advocates (LASA) hosted discussion groups that included parents of self-advocates as well as their children. These families had been making decisions as they had assumed that their children would not be able to know better. After some training, parents realized that they had underestimated their children's abilities. Parents were able to recognize the growth in their children.

What's happening around the world?

Myanmar – Discussions were held with a group of students where it was identified that the students needed the opportunity to make decisions.

They organized a weekend sleepover at school, where the students were able to exercise decision making in things such as what food to prepare.



Supported Decision Making

What's happening around the world?

Zanzibar - The Zanzibar Association for People with Developmental Disabilities (ZAPDD) told us that people with intellectual disabilities are systematically denied the right to self-determination in Africa; however, there have been some recent moves to models of support that enable supported decision making.



What's happening around the world?

Bulgaria - In Bulgaria, the Bulgarian Association for Persons with Intellectual Disabilities (BAPID) shared their experiences, lessons learned, and personal stories from participants regarding their pilot project *'Empowering people with intellectual disabilities – Next Steps'*. Through this work, BAPID is establishing a supported decision making model, implementing supported decision making as an alternative to guardianship for persons with intellectual disabilities that are currently under guardianship or at risk to be placed under guardianship.

Supported Decision Making

What's happening around the world?

Mexico – The Confederación Mexicana de Organizaciones en Favor de la Persona con Discapacidad Intelectual (CONFE) created a discussion strategy using the Right to Decide Campaign tools, resulting in 13 associations hosting over 65 focus groups of families, self-advocates, teachers, and service providers. Facilitated discussions and CONFE's plain language and picture participation tools helped to keep the conversation focused



What's happening around the world?

British Columbia's Representative Agreement

- A person with cognitive challenges authorizes a third party to act on his or her behalf for a broad range of personal and financial decisions
- The person retains legal capacity, must be consulted by the representative,
- And can revoke the agreement at any time



What's happening around the world?

British Columbia –

The Representation Agreements Act presumes capacity:

(1) Until the contrary is demonstrated, every adult is presumed capable of making, changing or revoking a representation agreement, and making decisions about personal care, health care and legal matters and about the adult's financial, business and assets.

(2) An adult's way of communicating with others is not grounds for deciding that he or she is incapable of understanding anything referred to in subsection.

What's happening around the world?

Sweden - The PO-Skåne or Personal Ombudsman is a national system that provides supports in decision-making for persons with severe mental or psychosocial disabilities.

The Personal Ombudsman is a professional who...

- Establishes a relationship with the person
- Assists the person to take control of their life
- Does NOT make decisions for the person but does represent the person
- Must be 100% on the side of the person

What's happening around the world?

United Kingdom –

The Mental Capacity Act was passed in 2005:

- **A presumption of capacity**

Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless proved otherwise.

- **The right for individuals to be supported to make their own decisions**

People must be given all appropriate help before anyone concludes that they cannot make their own decisions.

Mental Capacity Act 2005

Capacity is the ability to make a specific decision. Capacity will vary according to the complexity of the decision and the individual's circumstances. It can also vary over time.

A lack of capacity could be due to:

- A stroke or brain injury
- A mental health problem
- Dementia
- A learning disability
- Confusion, drowsiness or unconsciousness because of an illness or the treatment for it
- Substance misuse

Mental Capacity Act 2005

- That the individuals must retain the **right to make what might be seen as eccentric or unwise decisions**
- **Best interests** - anything done for or on behalf of people without capacity must be in their best interests, based on their preferences
- Least restrictive intervention - anything done for or on the behalf of people without capacity should be the **least restrictive of their basic rights and freedoms**

Where SDM Is Working Now...

- Any assessment of capacity must be about the particular decision that has to be made at a particular time and is not about a range of decisions
- If someone cannot make complex decisions this does not mean that they cannot make simple decisions
- You cannot decide that someone lacks capacity based upon their age, appearance, condition, or behavior alone

IMCA Duties

The Independent Mental Capacity Advocate...

1. Supports the person who lacks capacity and represents their views and interests to the decision-maker
2. Obtains and evaluates information
3. Learns about person's wishes, feelings, beliefs & values
4. Ascertains alternative courses of action
5. Obtains a second opinion, if necessary
6. Prepares a report

The IMCA can challenge the decision-maker if they disagree with the decision made.

Tools Used In The UK

Measuring Our Efforts:

- What is the decision to be made?
- How has information been provided?
- How has the person been given informed choice?
- How was the information made accessible? What methods have been used to communicate the information?
- How does the person express themselves? How do they communicate their preferences?
- Who else can communicate effectively with the person?
- Can anyone else help their person express themselves?

Measuring our efforts

- What has been done to support the person in retaining the information?
- What is the best time for the person to understand information and feel at ease?
- Where is the best location to share information? What are the best surroundings to receive information?
- What is the timescale in which decision needs to be made?
- Could this decision be put off to a better time?
- Is a best interest meeting needed?

Tools Used In The UK

Supporting the person to make their own decision
(i.e. Best Interest Meeting):

- Circle of Support
- Identify the Decision in my Life
- How I must be involved
- What part of the decision I am in control of
- What part of the decision I need help with
- Who makes the final decision
- When will this be reviewed

Principles of SDM

- Supporting people to make and communicate their decisions increases capacity for more independent decision making
- A person with disabilities has the right to self-determination
- Presumes competence—all people can and do make decisions
- Learning about people is critical
- People learn new things as they have more experiences

#1 Principles underlying Decision Making

Person Centered (Lead, Directed, Driven) Planning

#2 Least Restrictive Alternative and Environments

Freedom, choice, liberty, protect person's rights, variance from person to person

#3 Informed consent

Know the alternatives, know the consequences, understand information, have accurate information, pros/cons, consult various people

#4 Substituted Judgement

What would the person decide if they could, people who know the person well

#5 Best Interest

Last resort, addressing the person's needs, safety, health, welfare, consider the person's preference without projecting values

Lighting the Way to Guardianship and Other Decision Making Alternatives
2010 Florida Developmental Disability Council Inc.

WARNING

Supported Decision Making is **NOT** about making a decision for the person:



SDM is About...

Increasing capacity by teaching people:

- What rights and responsibilities are
- How to make decisions
- How to exercise rights
- Why exercising rights and responsibilities is important

Ensuring people have the opportunity to make decisions:

- Whether they make the “right” decision or not and
- Learning from their decision making.

Types of Decisions

“Independent” Decision Making

- Extra time to make decisions
- Information in plain language or Easy to Read
- Information in multiple formats, including visual or audio
- Communication supports like assistive technology, interpretation, or translation
- Informal assistance
- Support to build self-advocacy capacity

Independent but not Alone 2014

Supported Decision Making

- Peer support
- Advocacy
- Personal support networks, formal representation agreements, or key supporters for assistance with some or all decision making
- Communication supports like assistive technology, interpretation, or translation

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Types of Decisions

Decision Making Complex Situations

- Many will struggle with complex decisions. Some have suggested “facilitated decision making” as a support when decisions are complex or when a person requires significant support or does not use traditional communication.

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HEALTH DECISIONS

Informal

- Exercise
- Diet
- Hygiene
- Smoking
- Birth control

Formal

- Medical procedures
- Sterilization
- Consent to treatment

FINANCIAL DECISIONS

Informal

- Spending money
- Budgeting

Formal

- Bank Account
- Wills
- Investment
- Credit

PERSONAL DECISIONS

Informal

- Where to live
- Relationships
- Employment
- Education
- Civic participation

Formal

- Housing (Rent/Buy)
- Employment contracts
- Voting

MY SELF

- People are connected to natural support networks.
- People have intimate relationships.
- People are safe.
- People have the best possible health.
- People exercise rights.
- People are treated fairly.
- People are free from abuse and neglect.
- People experience continuity and security.
- People decide when to share personal information.

MY WORLD

- People choose where and with whom they live.
- People choose where they work.
- People use their environments.
- People live in integrated environments.
- People interact with other members of the community.
- People perform different social roles.
- People choose services.

MY DREAMS

- People choose personal goals.
- People realize personal goals.
- People participate in the life of the community.
- People have friends.
- People are respected.

All of the Personal Outcome Measures require us to know the person's preferences for their own lives.

What does the data tell us?

		1993-1998	1999-2004	2005-2009	2010-2013	All Data Average
My Self	connected to natural support networks	70%	61%	59%	68%	63%
	have intimate relationships	72%	75%	67%	64%	70%
	are safe	88%	84%	89%	82%	86%
	have best possible health	76%	79%	78%	76%	76%
	exercise rights	33%	55%	67%	73%	52%
	are treated fairly	43%	61%	72%	73%	59%
	are free from abuse and neglect	81%	83%	82%	79%	82%
	experience continuity and security	86%	77%	76%	73%	79%
	decide when to share personal information	86%	71%	77%	79%	76%
My World	choose where and with whom they live	44%	46%	53%	49%	47%
	choose where they work	36%	41%	49%	44%	41%
	use their environments	74%	76%	79%	76%	76%
	live-in integrated environments	40%	48%	45%	65%	46%
	interact with members of the community	67%	76%	75%	75%	73%
	perform different social roles	45%	43%	41%	47%	42%
	choose services	56%	58%	61%	62%	57%
My Dreams	choose personal goals	37%	54%	65%	61%	52%
	realize personal goals	67%	73%	83%	75%	75%
	participate in life of the community	70%	61%	65%	71%	65%
	have friends	53%	52%	57%	58%	54%
	are respected	66%	78%	85%	78%	76%

Personal Outcome Measures[®]

- Having conversations gives us information we don't get from typical assessments and reports

Ask The Right Questions:

- What do you want?
- What's important to you?
- What support do you want or need?

What will be do with our learning?

Promotes Self-Determination

- The right to self-determination is a fundamental right.
- It is the foundation for promoting opportunities for a person with disabilities to participate in the decision-making process in all aspects of his or her life.
- Self-determination recognizes that all people are valuable, capable people who deserve to be treated with respect and the same consideration that everyone has a right to expect.

Self - Determination

- People are –
 - Valuable
 - Capable
 - Deserve to be treated with respect
- The right, opportunity and power to make meaningful choices
- REAL choice



Self - Determination

Even if someone receives decision-making assistance, that person must have the final say over the decisions that are made, and he or she must ultimately be allowed to face the consequences of his/her decisions.



Lighting the Way to Guardianship and Other Decision Making Alternatives
2010 Florida Developmental Disability Council Inc.

Self - Determination

All people should have control over decisions that affect their life...

- Where to live
- Marry
- Have children
- Work
- Spend money
- Vote



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Presumes Competence

- All people can and do make decisions.
- Most people have supports to make decisions.
- A person with disabilities may need formal supports to gain experience and knowledge in understanding and evaluating their options and possible consequences, and communicating their decisions.

Dignity of Risk

- Everything has an element of risk
- We can learn valuable things from experience
- We must take care to find balance and not set people up for failure
- Informed Risk

Can you think of a time when you learned from a mistake?

What were the benefits of this?

Least Restrictive

In small groups – work through some least restrictive supports for the following situations.

- Someone lives in their own apartment with 24 hour support. They get up in the night and eat raw bacon.
- Someone has epilepsy and smokes. When they smoke on the couch and have a seizure the lit cigarette burns the couch.

TOOLS

- Not knowing what choices are out there for me
- Not being told the information
- The information is not accessible to me – it is too complicated if it's given to me at all

- Information that is: clear, accessible, and easy to read, with simple language and no jargon
- Information in video or audio format
- Lists of possible choices
- 'Tester sessions' when I can practice making decisions
- Time – to understand, to express myself, and to make decisions

SKILLS

- Lack of knowledge on how to communicate my choices
- Lack of confidence
- Fear

- Confidence!!
To say yes and to say no.
- Knowing where I can go to get advice
- Learning how to talk to my support workers, social worker, and family members about my decisions

RELATIONSHIPS

- Families and other people make it hard to let me make my own decisions: they are overprotective
- People still see me as a child and treat me as such
- People think I won't understand
- The staff are supposed to support me, but they run my life
- People around me do not believe I can decide

- I need good trusting relationships with the professionals in my life
- I need to be able to talk to people about the problems I have in order to know the options, and then I can make my decision
- I need a key worker to support my decisions around specific things
- I need the person who comes with me to insist that the professional or third party speak to me directly

OPPORTUNITY

- Bad past experiences
- Other people don't want me to make mistakes
- I am ignored or excluded
- I want to be able to go out at the times I want, shop where I want, and make decisions on what time I do things – not when or where it suits the staff

- I need to see and try new things to find out what I want and like to do

Learning About People

- Learning about what is important to the person and how best to support the person provides opportunities for personal growth
- Supports are personalized and may change based on what kind of decision is being made
- Making decisions is a learning experience...positive and negative outcomes

Supported Decision Making

Next Steps – People we support

- Support the person or people you know to make decisions
- Learn about what's important to the person or people you support
- Always include the person in decisions about their life
- Listen

- Self Advocacy

This is the most powerful way to see change. When people gather as a collective voice based on their first hand experience – CHANGE HAPPENS



- Circles of Support –

- People who love and care about the person
- People who promote the person's decisions
- People who are connected
- People who are committed



There must be a balance found – family, friends, professionals

Next Steps - Supports

- Practicing decision making
- Respect the 'will' and 'preference' of a person
- Adding supports to the person's unique abilities
- Free from coercion
- Information - Making things easy to understand
- Expression - especially for people with significant support needs
- Stopping practices that promote segregation

Supporters May:

- Access, collect, or obtain or assist the person to access, collect, or obtain information that is relevant to future decisions
- Assist the person in understanding that information
- Assist the person to understand options, responsibilities and consequences of decisions so the adult can make a decision
- Communicate or assist the person in communicating the decision

Next steps - Families

- Families need support to address their fears about decision making
- Families need family support groups and family organizations to share success stories
- Families need the opportunity to use peer to peer support strategies and parent to parent support groups
- Families need support to understand what is required of them to help their children and others to respect their right to make decisions

Next steps - Families

- Families need community to focus on a person's rights and have high expectations for their sons and daughters
- Families need real-life examples of people taking different paths and using different decision making methods so the discussion moves away from being hypothetical
- Families must share stories that illustrate what worked and what did not work in different situations
- Families need strategic partnerships to address and advocate for supported decision making in everyday life decisions and formal policy

Next steps - Families

- Families need information on how people explore different issues and circumstances, so that everyone can understand how people with very different abilities can take charge of their lives
- Families need to address the most complex issues for families: safety, protection, and “the big decisions”

Next Steps – Organizations

- Create a culture that actively learns about and honors people's decisions
- Develop personalized plans for SDM
- Develop systems that support staff when they have to support someone to do things that may not be the “best” decision
- Be a learning organization

Next Steps – Systems

- Support individuals and organizations to do the right thing
- Develop a culture that promotes Supported Decision Making
- Propose legislation that promotes Supported Decision Making

Model Legislation

ASAN has developed model legislation with the purpose:

“to create an alternative to guardianship, maximize autonomy, and improve health care outcomes for adults with disabilities by permitting adults with disabilities to name supporters to help them understand health-related information and options so they can make their own health care decisions.”

Agreement

A signed agreement:

- Details the responsibilities and the limitations of the supporter
- Identifies the supporter and/or supporters
- Can be changed by the person at any time

What still needs to happen?

- Awareness, accessibility and understanding
- State processes
- Review policy and procedures
- Review guardianship law
- Advocacy
- Common practice
- Respectful culture change for families with guardianship

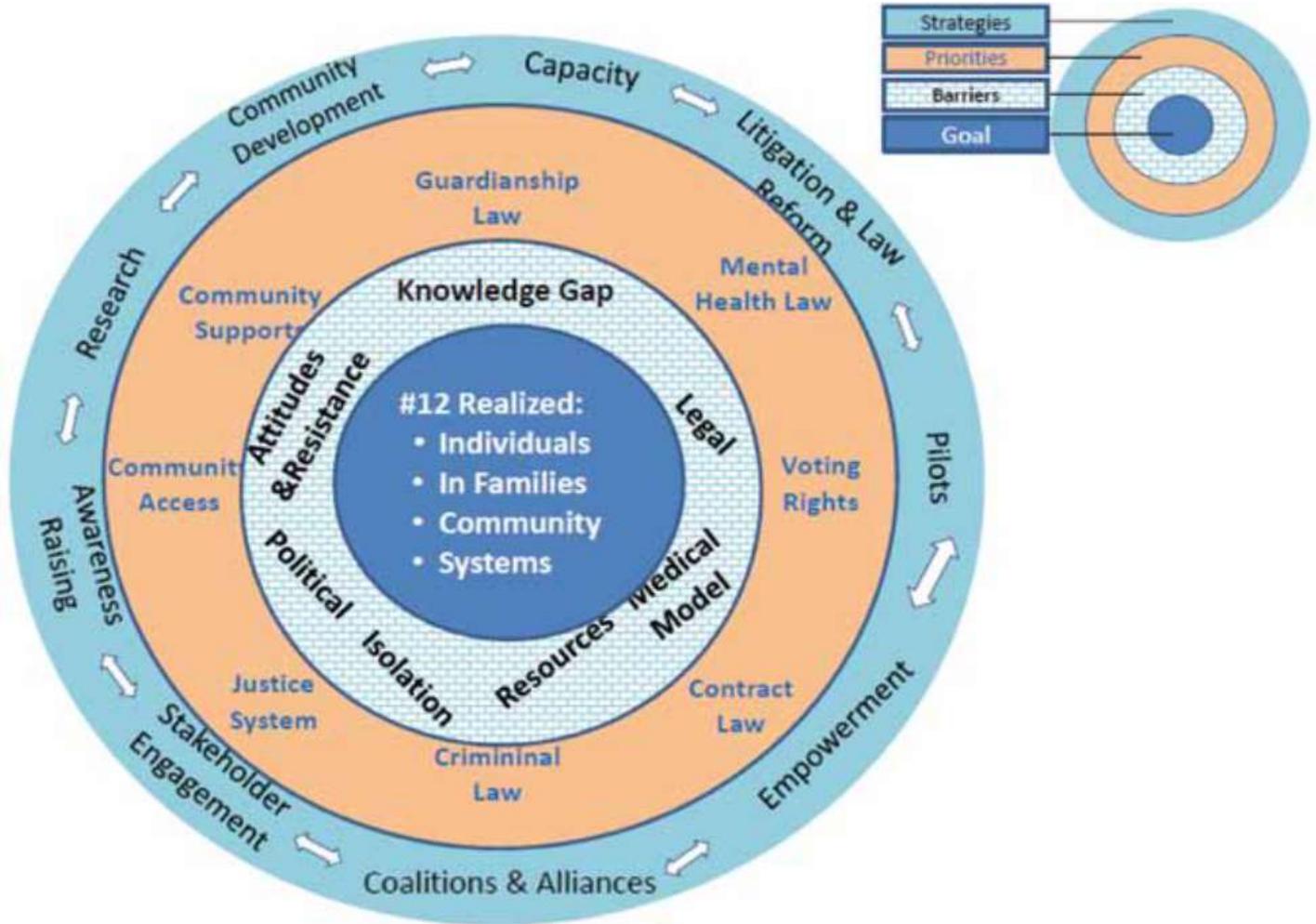
Equal Rights

Equal right of people with intellectual disabilities to direct their own lives will require:

- Attitudinal change
- Transformations in the way supports are provided by government and communities
- Legislative reform
- Public policy transformation
- Development and recognition of law for Supported Decision Making, networks and processes

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Supported Decision Making



“Denial of such rights is often cloaked in language of ‘protection’ and best interests. It is assumed the person with an Intellectual Disability cannot make or express choices.

Underlying much of the prejudice against persons with Intellectual Disability is far more than a paternalistic attitude – it is a failure to recognize their humanity and personhood.”

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TO KEEP PUSHING SDM FORWARD:

- What will you do today?
- What will you do tomorrow?
- How will you be the change?



Questions, Thoughts & Suggestions

For more information

- ASAN | Autistic Self Advocacy Network
www.autisticadvocacy.org
- Quality Trust for Individuals with Disabilities
www.dcqualitytrust.org
- CQL | The Council on Quality and Leadership
www.c-q-l.org



OCT 20-21
St. Louis, MO



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CQL is dedicated to the definition, measurement and improvement of personal quality of life for people receiving human services and supports.

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