



Speaking Up For Us

Maine's Self Advocacy Network

Introductions

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Agenda

Learn about Self-Advocacy and Speaking
Up For Us

Learn about Self-Determination

Learn about the HCBS Settings Rule

Examples of Informed Choice



Self-Advocacy in Maine

In Maine, our self advocacy organization is called Speaking Up For Us.

We are part of a nationwide network of people who identify as self-advocates.

We work closely with the DD Network made up of:

Maine Developmental Disabilities Council
Disability Rights Maine
Center for Inclusion and Disability Services.



What is Self-Advocacy?

Self Advocacy is part of the Civil Rights Movement for people with Intellectual/Developmental Disabilities to be empowered and in control of their own lives and make decisions.

The Self-Advocacy Movement is about PWDD speaking up for themselves to be able to say what they want in their lives, even if they need to have the support of others.

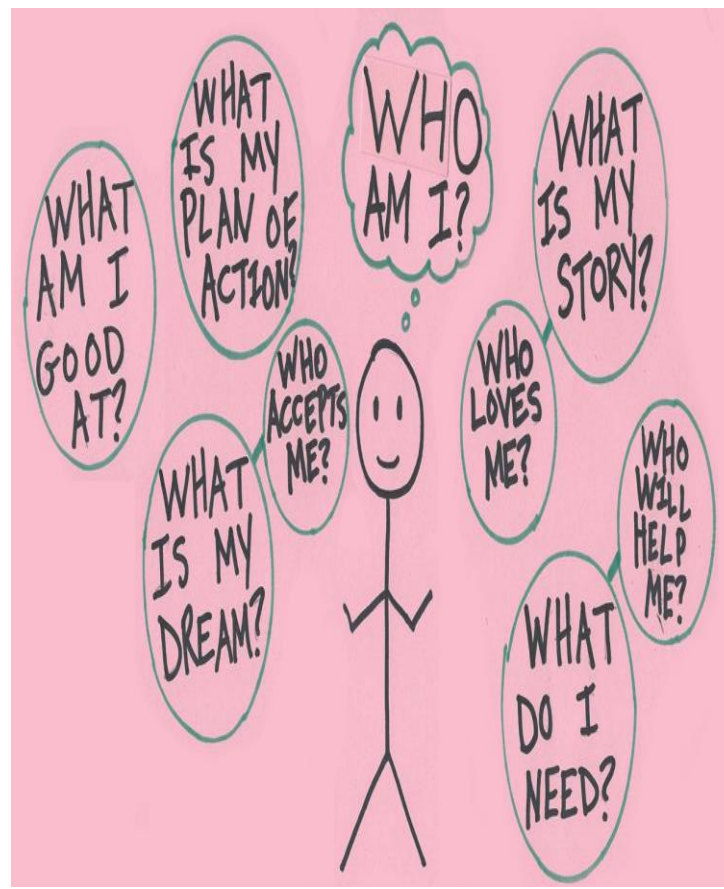


What is Self-Determination?

Self-Determination is a process that is different for every individual based on what that individual thinks they need or want to have a meaningful life.


Self-Determination is person-centered and person-directed. It acknowledges the rights of people with disabilities to take charge and responsibility of their own lives.





What is Self-Advocacy?

https://www.youtube.com/watch?app=desktop&v=sOX3LWUD2_g

A portrait of a man with dark hair, a mustache, and glasses, smiling. He is wearing a dark-colored shirt. The background is dark and out of focus.

BERNARD CARARELLO

Self Advocacy to Self Determination



Importance of Self-Advocacy & Self-Determination

Self Advocacy is so important because it is an opportunity for self-advocates to gain the knowledge to succeed and to make decisions about their own lives.

Self-advocates feel they are the best resource to have a say in their own lives. "Nothing about us, without us."

Historically, PWDD had no voice or option to make these decisions for themselves. They had no control over their money, services, where to live, hobbies, careers, etc.





Maine Developmental Disabilities Council

Advocacy ~ Capacity Building ~ Systems Change

Explore More DD History

[Home - Out of the Shadows \(shadowsofpineland.org\)](http://shadowsofpineland.org)

How does it work?

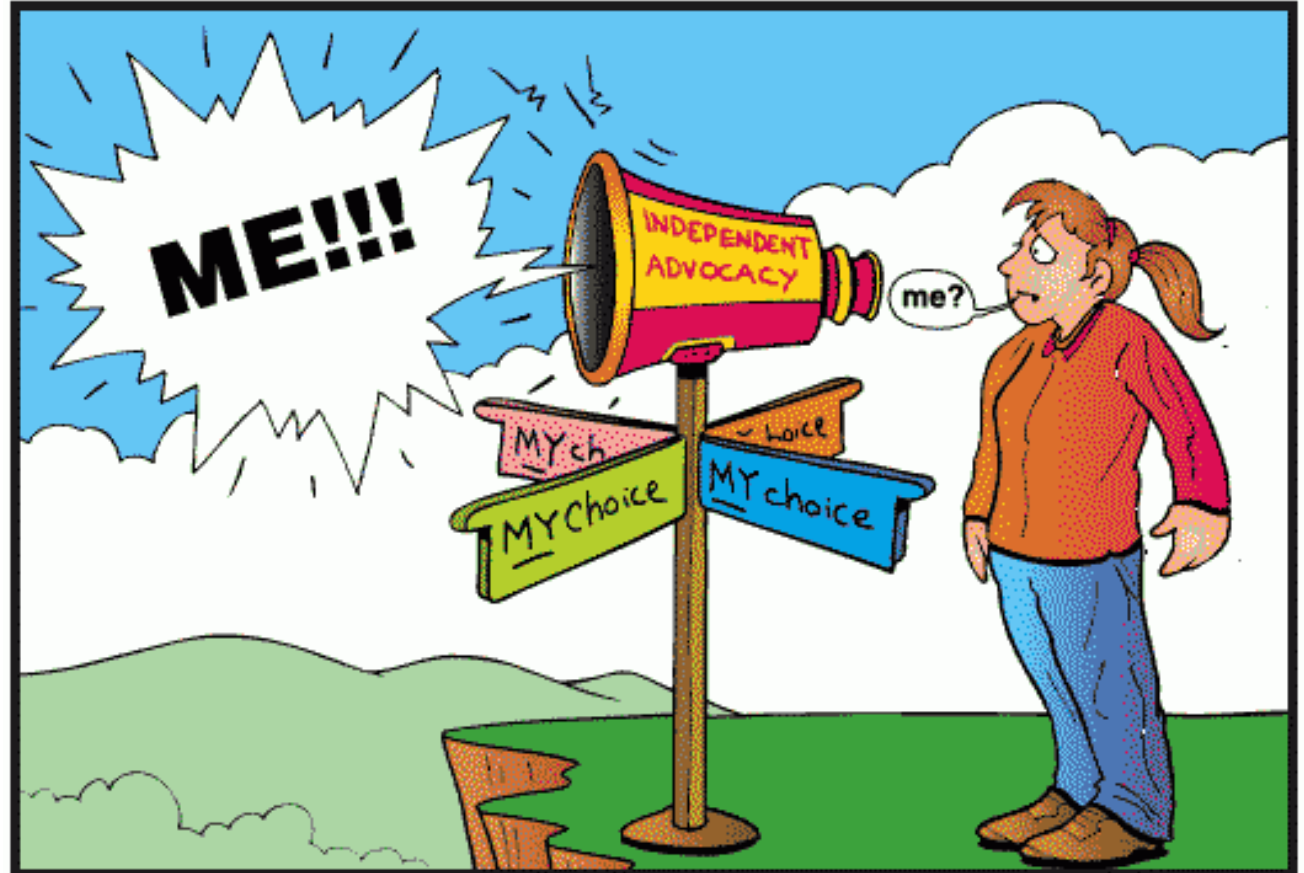
How does Self-Advocacy and Self-Determination work?

Self-Advocates can advocate on different levels:

Personal

Community

Policy-Local, State, Federal



What do Self-Advocates speak up ABOUT?

What do **YOU** want to speak up about?



Independent Living



- Support, Aids and Equipment
- Personal Care
- Shopping
- Banking
- Budgeting

Employment



- Flexible hours
- Accommodations
- Resume Writing
- Job Search
- Job Coach
- Discrimination

- Accessible House
- Assisted Living
- Needs Assessment
- Finances
- Own Apartment
- Shared Living
- Buying a House

Housing



Medical



- Diagnosis and Treatment
- Referrals to Doctors
- Medication Management

Relationships



- Family and Friends
- Romantic
- Coworkers
- Neighbors
- Support Staff and Providers

Access

- Remove Physical Barriers
- Community Access
- Large Print, Braille
- Audio Recording



Transportation



- Getting Driver's License
- Owning a Car
- Public Transportation
- Parking

Education



- Adult Education
- Learning New Skills
- College
- Learning Accommodations

Recreation



- Hobbies
- Relaxation
- Clubs
- Civic Organizations

To learn more about speaking up in your life join us!

Speaking Up For Us

Maine's Self Advocacy Network
sufumaine.org (207) 956-1004



Policies: HCBS Rule Changes

*In 2014 the federal Centers for Medicare and Medicaid Services (CMS) released a new rule for HCBS.

*The rule says that people who receive home and community-based services and supports ***funded through Medicaid*** must receive those services and supports in settings that meet specific standards.

*This rule was made so that all services are truly home and community-based.



Policies: HCBS Rule Changes

*This means that individuals receiving services in these settings have full access to the greater community and can enjoy all benefits of community living.

*The overall goal is to give people community experiences that are very different from what an institution would offer.

[Home and Community Based Services \(HCBS\) Settings Rule Transition Initiative | Department of Health and Human Services \(maine.gov\)](#)

[Home & Community Based Services Final Regulation | Medicaid](#)





**DISABILITY
RIGHTS
MAINE** 

Disability Rights Maine & SUFU Board Chair Webinar

[Disability Rights Maine \(en-US\) \(drme.org\)](https://drme.org)

Your Services
Should be All
About You!



- [Your Services Should Be All About You - YouTube](#)

Your Services Should be All About YOU!



Informed Choice: A Decision-Making Process

The individual makes a decision based on COMPLETE information.

The individual has accurate information about what is needed to complete their goals.

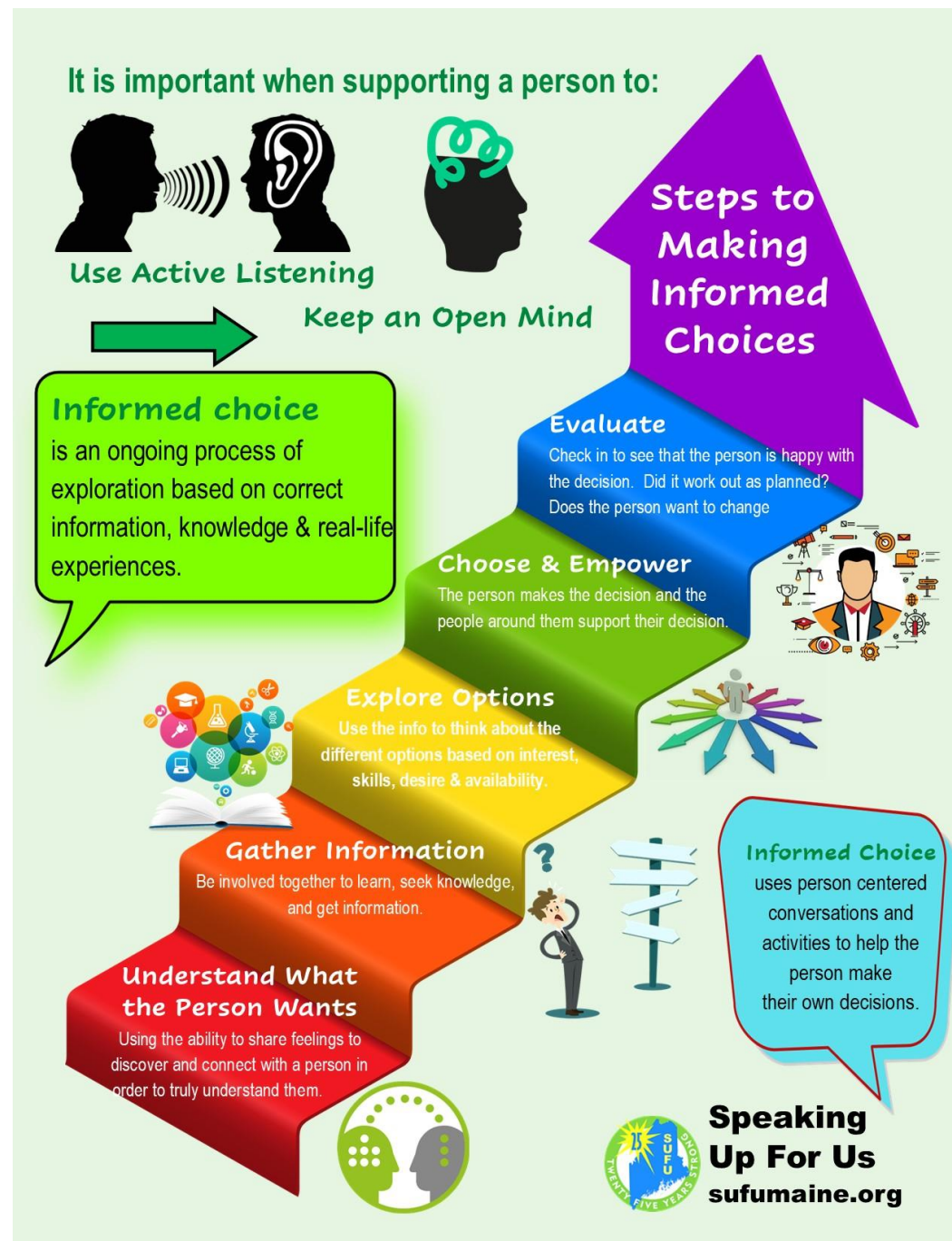
When the individual understands all the options and the risks vs benefit of their decision.

Informed choice is an ongoing process and happens through person-centered conversations and activities.

It is a circular, recurring process that doesn't happen only one time.



Steps to Making Informed Choices



Informed Choice Is NOT

Someone else offering a choice between two or three options.

A pre-selected calendar of activities that are decided on by an individual's support staff.

Someone else making all the decisions for the person.

Remember, Informed Choice aligns with Self-Determination.

Individuals have a right to change their mind!



Decision Making Tools



[Decision-Making Strategies - YouTube](#)

The Rational Decision-Making Process

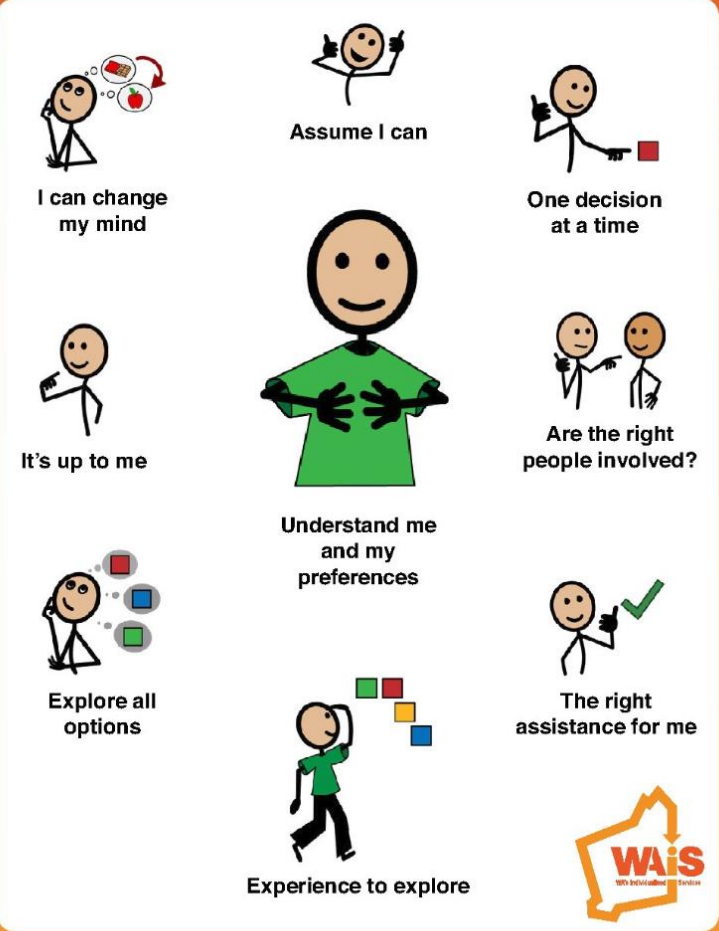


Supported Decision Making

Supported decision making (SDM) is a tool that **allows people with disabilities to retain their decision-making capacity by choosing supporters to help them make choices.**

A person using SDM selects trusted advisors, such as friends, family members, or professionals, to serve as supporters.

SUPPORTED DECISION MAKING PRINCIPLES



The infographic features ten principles arranged around a central figure of a person in a green shirt. Each principle is accompanied by a stick figure icon and a text label. The principles are: 'I can change my mind' (top left), 'Assume I can' (top center), 'One decision at a time' (top right), 'It's up to me' (middle left), 'Understand me and my preferences' (center), 'Are the right people involved?' (middle right), 'Explore all options' (bottom left), 'Experience to explore' (bottom center), 'The right assistance for me' (bottom right), and a logo for 'Wais' (bottom right corner). The background is orange with a white border around the central content area.

- I can change my mind
- Assume I can
- One decision at a time
- It's up to me
- Understand me and my preferences
- Are the right people involved?
- Explore all options
- Experience to explore
- The right assistance for me

Wais
With Individualised Services

www.waindividualisedservices.org.au

Person Centered Planning and Goal Setting

Decision making can also happen during the Person- Centered Planning process.

There are a lot of tools available for Person Centered Planning.

Charting the Life Course: [Person Centered – LifeCourse Nexus \(lifecoursetools.com\)](http://lifecoursetools.com)



Dignity of Risk

It is the Right of the Individual (You and I!) to take risks when participating in life experiences.

It means that all experiences may not be positive, but you get to determine that on your own.

It means having the choice to take a risk.

It means learning from the risk you take.

It means experiencing any negative consequences.

It means experiencing positive outcomes.

It also means knowing you had the chance to make a choice on your own.





Informed Decision Making Video

[NYS DSP Core Competencies Informed Decision Making - YouTube](#)



Join US!

Consider Joining Speaking Up For Us

Network of other self advocates, you are not in this alone!

Gain information, learn about issues

Learn skills to use your voice

Explore different experiences

Socialize with Friends

Become a Leader- Leadership Program

Advocacy Day Program at the Statehouse

Volunteer Opportunities for Inclusion

Annual Statewide Conference



Meet Self Advocates Across Maine & Nationally

Maine Statewide Call on Tuesdays

Local Chapters in Maine Communities

SARTAC- Self-Advocacy Resource & Technical
Assistance Center

SABE- Self-Advocate Becoming Empowered

NEAT- North-East Advocates Together



RESOURCES FOR MORE INFORMATION

- Website: sufumaine.org
- Phone: (207) 956-1004
- Email: Monique Stairs mstairs@sufumaine.org
- Email Laurie Coldwell lcoldwell@sufumaine.org
- [Informed Choice Toolkit \(db101.org\)](http://db101.org)
- [Microsoft Word - Chapter5.doc \(osdaohio.org\)](http://osdaohio.org)

Questions?

