

# Guardianship/Supported Decision Making Research

This document contains research completed by the COGA Task Force. Subgroup members included John Kirkwood and Jennie Delisi.

## Goal of the document

The goal of this document is to support increased involvement of people with cognitive disabilities to be included in the process of the creation of W3C guidelines. Please refer to [Making Content for People with Cognitive Disabilities and Learning Disabilities](#) for more information. The specific goal is to identify the potential blocking of participation by some individuals due to support needs, and address any potential blockers for involvement in the process. It is recommended that the application and participation process be reviewed. This would better incorporate the needs of those with guardianship and other cognitive support needs to effectively participate in community and work groups as members.

The Target audiences for this document: COGA, AG, W3C including both business lines and legal.

The format for this document is:

- [Questions not yet resolved](#)
- [Recommendations](#)
- [Problem Statement](#)

## Problem Statement

Some individuals may find W3C processes inaccessible or too challenging or to participate in their current form. This unintentionally leaves some people out of the W3C process, including some with cognitive disabilities. Definitions of guardian and shared decision making are included in the next section. Effective participation in the current state of W3C membership may require the support of a shared decision maker or guardian in particular to:

- Have the ability to determine when they are safe in online interactions
- Participate in legal agreements/contracts (understand them, legally be able to sign on their own behalf, be sure to follow through with them/adhere to them, etc.)
- Manage complex communications through multiple methods which includes tracking and responding to communications, scheduling time to participate, etc.
  - Example: following a thread through multiple communication channels.
  - Example: Reviewing a document, and understanding the timing of responses, method for filing issues, and the protocol for participating in meetings.
  - Example: finding the status of a current topic, which working group is currently addressing it and how, which communication channel/tool contains the information (minutes, Github, task list, working draft).

Some of these individuals may have guardians or support because their disability may impact their ability to:

- Understand the impacts of risks (immediate and long-term) around digital and other publications that could include their name and/or personal details
- Understand complex communications such as contracts/agreements for participation
- Determine who to trust in online interactions
- Independently make decisions related to these risks

Some information related to challenges experienced accessing digital information is personal. Participation in W3C working groups sometimes involves sharing about personal challenges experienced. Navigating when and how to share these personal experiences without making a person more vulnerable is a complex process. Some people will need support to navigate this.

Some communities within the disability community are vulnerable to targeted attacks, especially in online interactions. These can include becoming a target of online predators.

- One example: robocalls and phishing attacks targeting older adults with limited computer skills or age-related cognitive issues.
- Another example: in online interactions, when a person's identity is available through publications (official notes, meeting minutes, use case publications), people they would not encounter in their daily interactions may become aware of them. This can be important if:
  - The person shares personal use cases related to their disability
  - the person's address is findable on the internet.

It should be noted, some very talented individuals are currently unable to fully participate or share at their full capacity, or be a productive member of the working and community groups. With other options, people who would be otherwise unable to participate could provide valuable input that would improve the web for many. People are more self-directed, self-determined, more effective and successful when they have an opportunity to use the cognitive supports they need.

In addition, agreements such as the Invited Expert Collaborator Application has language that may be of concern in a guardianship situation. [Invited Expert and Collaborator Agreement - W3C:](#)

“W3C may, at its discretion, grant Invited Experts access to Member confidential information, generally based on the level of confidentiality of meeting records and other proceedings described in a group charter. This access includes mailing-lists, website, tools, teleconferences and meetings. W3C seeks to ensure that all Invited Experts in a given W3C Group have the access necessary to enable the group to conduct its work.” W3C AC Representative language may be one model to consider for how to address guardianship situations or the need for shared decision making and/or cognitive support, in terms of legal language. This is not the only model or necessarily satisfy all needs, but it is a precedent.

## Guardianship, Shared Decision Making, and Cognitive Support

Guardianship is a legal status. Individuals can be co-guardians of themselves. This individual provides a type of cognitive support for decision making. For example, an individual may have a guardian assigned to them but they retain the ability to participate legally in decisions made on their behalf. There are times where a person may request this legal representative (guardian) to sign official or complex documents on their behalf.

In some cases guardianship may be too restrictive. When appropriate for an individual, shared decision making is increasingly used instead of guardianship. This model is becoming increasingly popular for those with cognitive disabilities.

Some people with cognitive disabilities can better participate with, for example:

- shared or supported decision-making,
- supports provided by another person or cognitive support service provider (examples: supported employment provider, residential care provider)
- involvement of their legal guardian (example: for signing agreements).

This may benefit current members of the W3C as well as new members, and potential community members.

Some examples of when a guardian, shared decision maker, or support person could be involved may include:

- Joining groups and subgroups,
- Deciding when the person's full name can be included in public minutes and credits (note: in some locations the ability to publicize a person's full name is always the decision of the individual regardless of guardianship status);
- Supporting an individual to decide if a personal story should be shared, is private, potentially damaging, or contains personal health information. Example: a guardian would prevent someone from potentially publishing something that might cause others risk, such as a stories about a specific company's website, personnel, or process.
- Provide administrative, communication, decision-making, or cognitive supports as needed
- Agree to travel to, or host, a meeting
- Other tasks identified by the guardian as being affected by guardianship.

Each individual may have unique needs. Some may need only one of these options and may wish to participate independently in all other ways. Others may need more than one of these options.

It should be noted that there is a movement away from guardianship and towards shared decision making in some places.

## Recommendation: Proposed Additional Membership Options

The COGA Task Force recommends that alternative membership options for community group and W3C participation are available. These could include the following options.

## Before Applying to be an Invited Expert or Community Member

**An opportunity and invitation should be provided for a person considering membership to work with a guardian or shared decision maker to review documents before completing the agreement.**

## Helping People Participate

**A person could choose to have their guardian, or another person they identify, be involved to help with their participation (either as a named member or be a partner in their membership).** This could include but is not limited to supporting the person to:

- Review content prior to publication.
- Manage their communications with the group.

**A person with a guardian can have a liaison-type role for the guardian who approves their participation, and then the individual independently participates.** In some cases, guardians may only need to be involved for contract or legal document signatures. For some countries, guardianship may involve authorizing publication of an individual's name or contains specifically identifying information.

## Support Person or Organization is officially “The Member’s Representative”

**A support organization or person could be the member (on behalf of an individual) in order to facilitate participation by an individual that may:**

- Prefer or need not to be named, or manage the communications.
- Help facilitate access to meetings and materials. Example: some individuals may not do well with independent use of a computer because they have a disability impacting their judgment but they can and do complete many tasks independently on a computer as long as they are supervised.
  - To ensure their safety, with proper support, they may be able to provide valuable input and ideas for the work of the W3C. An organization could be a supported employment organization, a congregate living facility, or a "self-advocacy" organization.
- Example: Fred lives in a group home. The group home is the official member’s representative. Fred is not named in communications or publications.

## A Process for Those with Proposed Additional Membership Options

**A process should be available for the individual to change their designated support person/organization/guardian**

- Example: a person selects a support professional they use regularly, then that person takes a different job.
- Example 2: a person moves from one supported employment organization to another.

## Questions Not Yet Resolved: Most Likely for Legal Team

- A. For those unable to sign a contract due to legal guardian status, 2 aspects could be considered:

- To participate, could the person signing a contract could attest that if they have a legal guardian and they have shared this document with them?
  - Could a liaison style role be available for when a person with a legal guardian only needs legal consent for certain aspects of participation like contract signing, but provides no other support role? This would be similar to potential members who are not yet of age of consent to sign a contract (example under 18 years of age in most American states). This would be necessary in legal activities where a person's signature may not be valid on its own.
- B. It should be noted, If the W3C did not find a way to provide appropriate access for people that have guardians this seemingly could put the W3C at risk for barring entry to participation by individuals with specific types of disabilities for which guardianship is their accommodation. Having a plan and a process for when individuals need this type of accommodation would be a risk mitigation.
- If a person's disability is related to judgement, and publishing their name and/or email address could be deemed to make them vulnerable (known to people they would not otherwise encounter since it is on the internet) how best to get permission to post their name and/or email.

Possible option:

For those that are not their own guardian, could a service provider of their choosing (like a group home) or a parent/guardian become a member as an "invited expert" and be the name on file/communication channel. Then the individual could participate without being named (unless they choose to be), and would not have to manage all the communications - unless they wanted to do so.

## Research

Research study: [A process of decision-making support: Exploring supported decision-making practice in Canada A process of decision-making support:   
https://www.tandfonline.com/doi/full/10.3109/13668250.2020.1789269](https://www.tandfonline.com/doi/full/10.3109/13668250.2020.1789269)

## Older Adults and the Web

While individuals discussed in this study may be their own guardians, their cognitive disabilities may be declining. Some of them could be entering into times where someone will be deemed their guardian. This does not mean they would no longer be able or interested in using the web.

## Risks for People with Cognitive Disabilities of Using Digital and Other Publications Tools Like Social Media

Elderly individuals are more likely to be targeted by online financial fraud, and when they lose money, it's a higher amount than average, according to researchers.

[Research shows elderly individuals are more likely to be targeted by online fraud](https://www.cnn.com/2019/11/23/new-research-pinpoints-how-elderly-people-are-targeted-in-online-scams.html)

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## Guardianship Around the World

Each country handles guardianship cases in different ways but with the same goal of self determination for those with cognitive or intellectual disabilities.

### Australia

[https://www.international-guardianship.com/pdf/GBC/GBC\\_Australia.pdf](https://www.international-guardianship.com/pdf/GBC/GBC_Australia.pdf)

- "Each State and Territory has its own adult protection (guardianship) scheme and its own laws relating to enduring powers of attorney."
- "a Tribunal generally has to be satisfied after a hearing of an application that:...The disability causes the person to be incapable of making decisions relating to their finances or personal welfare..."
- "a represented person can:...stand as a candidate in an election,...enter into contracts - but a contract may be voided by an administrator or financial manager if the other party was on notice that the represented person lacked capacity to enter into that contract, the existence of the order is not determinative but may be persuasive in that issue..."

### Japan

[https://www.international-guardianship.com/pdf/GBC/GBC\\_Japan.pdf](https://www.international-guardianship.com/pdf/GBC/GBC_Japan.pdf)

- Doesn't seem to contain anything specific to what we are doing, unless the participation is considered to be valuable, or present information that makes the individual liable to a third party

### Canada

[https://www.international-guardianship.com/pdf/GBC/GBC\\_Canada.pdf](https://www.international-guardianship.com/pdf/GBC/GBC_Canada.pdf)

"The general trend in Canada is away from the use of court appointed guardians/guardianship in favour of finding and using more flexible, sensitive, effective and humane alternatives that respect both the adult's wishes and the adult's network (family, friends, etc.). Supported decision-making alternatives are growing by leaps and bounds, especially for people with developmental disabilities."

"Guardianship is not quite a dirty word, but we are getting there; it is definitely seen as undesirable, but a necessary evil."

## United Kingdom

There are separate Offices of the Public Guardian across England, Wales, Scotland and Northern Ireland that support Guardianship orders

<https://www.gov.uk/government/publications/requesting-information-about-a-guardianship-order> and <https://www.publicguardian-scotland.gov.uk/guardianship-orders>

The Scottish office also has a definition

"Guardian

a person appointed by the court to act as guardian in relation to the property, financial affairs or personal welfare of an adult with incapacity."

<https://www.publicguardian-scotland.gov.uk/general/terms-used>

There are various Legal Acts that cover the subject, but Mencap as a charity has a helpful set of guidelines including "Supporting someone to make a decision"

<https://www.mencap.org.uk/advice-and-support/mental-capacity-act>

## United States

[https://www.international-guardianship.com/pdf/GBC/GBC\\_USA.pdf](https://www.international-guardianship.com/pdf/GBC/GBC_USA.pdf)

- Nothing specific here about what we are reviewing, other than the fact that some pieces vary state by state

## Think College: Institute for Community Inclusion, UMASS Boston

[https://thinkcollege.net/general-site-search?search\\_api\\_views\\_fulltext=guardianship+definition&sort=created&order=desc](https://thinkcollege.net/general-site-search?search_api_views_fulltext=guardianship+definition&sort=created&order=desc)

Video: The Colby Act talks about both guardianship and the supportive decision-making model

Video found from link to the PACER Center, but is actually from DisabilityRightsFL also mentions in Transitioning to Adulthood Explained (<https://www.youtube.com/watch?v=XyJR8PIOFz8>) that there are alternatives to guardianship, including the supportive decision-making model.

## Gator: Guardianship Alternatives and Transfer of Rights

Gator Glossary:

<https://gator.communityinclusion.org/#glossary>

"Assignment/delegation of rights

refers to an arrangement where an adult student voluntarily authorizes another person to make educational decisions on their behalf, in the same way the student's parent would have done so while the student was a minor. Not all State laws recognize assignment or delegation of rights, and the rules of those that do so vary. Assignment or delegation of rights is an example of an alternative to guardianship."

"Guardianship

refers to a legal arrangement where one person (the "guardian") is appointed by a court to make decisions on behalf of another person. Often, but not always, courts will appoint guardians for adults who they believe are unable to make certain or all kinds of decisions on their own. States' laws regarding guardianship vary. Certain States use other terms, such as "conservatorship," in addition to or instead of "guardianship."

"Power of attorney

refers to a legal arrangement made between two adults where one (the "principal") voluntarily authorizes another (the "agent" or the "attorney-in-fact") to make certain legal, financial, medical, or other decisions on their behalf. States' laws regarding powers of attorney vary. A power of attorney is an example of an alternative to guardianship."

"Shared decision-making

refers to a legal arrangement where an adult student receiving special education services authorizes one or more others to participate in the student's educational decision-making processes. Currently, only the Commonwealth of Massachusetts formally recognizes this arrangement. Shared decision-making is an example of an alternative to guardianship."

## Information from Colleagues

From one of Jennie's colleagues:

"In our view, people under guardianship own their own name, face and voice and may participate in (organization name) offerings without going through their guardian."

Another colleague of Jennie's:

"The law and practices can vary by state as well so you will have to consult with the appropriate authorities in each state."

## Guardianship Consent Methodology

Example: With person with a cognitive disability "use a standard consent form. If the person signing it is a guardian, then we add that as their title. When the person with [IDD](#) [Intellectual and Development

Diabilities] is our client, we use a **plain language version** and **review it** with the client **in person** or **by phone**. “ [Disability Rights New York](#)”

## Definitions

Guardianship of Person Who is Intellectually Disabled or Developmentally Disabled

A certification from one physician and one psychologist or two physicians must be filed with the petition certifying that the person has a disability and is not able to manage his or her affairs because of intellectual disability, developmental disability or a traumatic head injury. The Surrogate's Court can appoint a guardian of the person, the property or both. [NYS Article 17-A Guardianship](#)

## Previous Discussions Around Consent for Content Usable (related discussions)

### From Jennie

The [Minnesota Olmstead Plan](#), for example, includes:

- The opportunity and freedom for meaningful choice, self-determination, and increased quality of life, through: opportunities for economic self-sufficiency and employment options; choices of living location and situation, and having supports needed to allow for these choices;
- Systemic change supports self-determination, through revised policies and practices across state government and the ongoing identification and development of opportunities beyond the choices available today; and
- Readily available information about rights, options, and risks and benefits of these options, and the ability to revisit choices over time.

On page 25 of the National Council on Disability's "[Turning Rights into Reality](#)" document, it says: "As the American Association on Intellectual and Developmental Disabilities and The Arc of the United States have jointly concluded: 'Less restrictive means of decision-making supports (e.g., health-care proxies, advance directives, supported decision-making, powers of attorney, notarized statements, representation agreements, etc.) should be tried and found to be ineffective in ensuring the individual's decision-making capacity before use of guardianship as an option is considered.'" "...service providers, family, judges, and others assume people with ID/DD cannot make decisions for themselves,<sup>16</sup> despite research to the contrary.<sup>17</sup>"

Here's a sentence to consider adding, but I am definitely open to edits and suggestions:

Any policy that involves information about providing consent, assent, or legal documents (including documents such as rental agreements), needs to ensure that the information can be used and

understood by the individual with a cognitive or learning disability. Even if they have a legal guardian, individuals should be provided an opportunity to review the information, ask questions, and request the information in a different format (and receive it) with enough time for them to review and ask questions.

## Response from Another COGA Member (Jennie to secure permission to add their name here)

Suggested revision:

“Any policy with information about consent and/or assent; and/or legal documents, including documents such as rental agreements, needs to ensure information can be understood by people with cognitive disabilities. Even if they have legal guardians, they should be provided an opportunity to review the information, ask questions, and request the information in a different format (and receive it) with enough time for them to review and ask questions.”

Notes

Learning disabilities are part of the cognitive-disability spectrum. Thus there is no need to specify them.

I added “and/or” because I am aware of litigation focused on “or” without “and”.

I removed some text to simplify the sentences. Consider breaking them up further into short sentences.

Consider removing “including documents such as rental agreements” if there is no important reason to specify it.

Note: Jennie prefers this over her previous suggestion.