

Keeping up With Informed Consent: Standards & Best Practices

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Agenda

Informed Consent

- The basics
- Further considerations
- FAQs

Questions





Informed Consent – The Basics

ACSLPA Guideline: Informed Consent for Service

Why is it so important to get consent right?

- It is a requirement of practice (See <u>Code of</u> Ethics and Standards of Practice 2.3)
- Consent is a foundation of ethical practice
 - Protect and respect autonomy and integrity
 - Understanding of services and options
 - Understanding of right to refuse/withdraw consent
- Significant implications for client and regulated member if not handled correctly





Informed Consent Discussions Should Address:

- The nature/purpose of the activity
- The name of the person most responsible
- The intended duration
- The benefits and risks associated
- Any alternatives
- Any likely consequences of delaying/refusing/accepting
- The option to refuse/withdraw at any time without fear of reprisal
- Opportunity to ask questions











Who can Provide Informed Consent for Service?

- Client or legally authorized representative
- Consider:
 - Capacity for informed consent



ACSLPA Position Statement: SLP Role in Supporting Capacity Assessment

Client wishes on the involvement of others



When Should Informed Consent for Service be Obtained?

- Prior to providing any professional service
 - Clinical screening
 - Assessment
 - Intervention
 - Participation in clinical research
- Substantial change in plan of care
- Change in diagnosis, symptoms, or circumstances
- Assignment of activities to support personnel
- Observation/participation from a student or volunteer



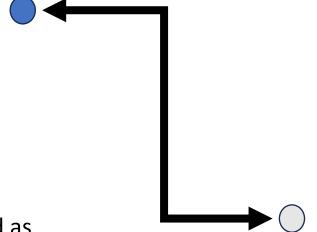
Who is Responsible for Obtaining Informed Consent for Service?

- Professional most responsible for care
 - Best positioned to answer questions about services
- When aspects of consent are assigned to others (e.g., distribution of consent for screening form):
 - Must ensure consent is valid and informed (what information is being provided)
 - Must be available to answer any questions from client



How Should Informed Consent for Service be Obtained?

- Free of influence
- Not a static, 'one-time' event
- Collaborative: interactive, two-way process
- Verbal/written
- Expressed/implied
- Right to refuse/discontinue at any time
- Translators/interpreters
- Negative consent*
 - Not the same as consent and should NOT be used as justification to proceed

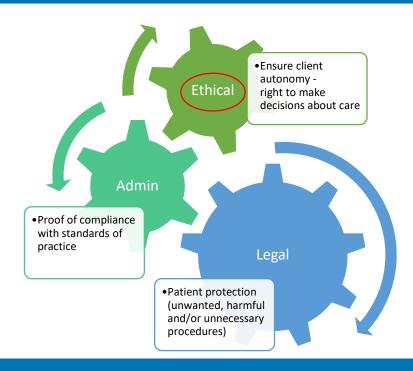






Informed Consent – Further Considerations

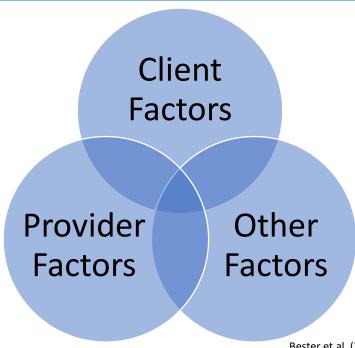
Purposes of Informed Consent



Hall et al. (2012)



Factors Impacting Informed Consent



Bester et al. (2016); Convie et al. (2020); Hall et al. (2012); Weiner, 2019)



Client Factors



Age, capacity, education (health literacy), etc.



(anxiety, fear, pain, medications, stress, overwhelmed, information overload, etc.)

Physical and mental state



preferences
(delegation or deferring to support person, provider)

Decision making



(avoid 'offending' provider, negative judgement)

Desire to be seen as

'model' client



Provider Factors



Demands on time



Power dynamic

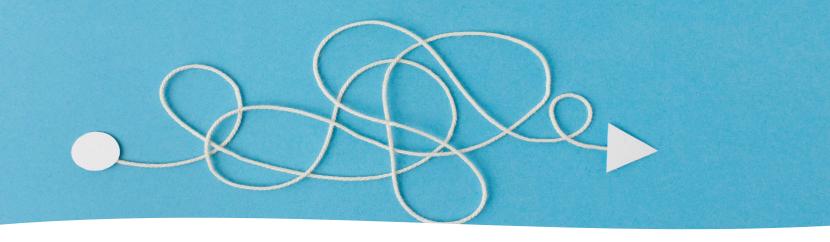
'Power over' position with clients



Ability to communicate important information (facilitate understanding)



Skill in determining how client wants to be involved in decision making



Other Factors

- General assumption that client will use information in a 'rational' way
- Illusion of choice for client
- Severity/type of issue
 - Routine, less invasive (e.g., speech sound assessment) versus more invasive procedure (e.g., FEES)
- Availability of linguistic/cultural accommodations
- Time given to process information and make decisions

Ethical Consent - Strategies to Consider

- Shared decision making
 - Elicit client values
 - Actively involve clients
- Involve decision making support people/surrogate (if desired by client)
 - Lessen decision fatigue / emotional load for client
- Avoid a one size fits all approach
 - Level of detail
 - Decision making preferences
 - Values and goals
 - Physical, emotional states
 - Cultural/societal norms



Ethical Consent - Strategies to Consider

- Use jargon free, simple, clear language
- Choice versus conditions of service
- Create space for more processing time
- Include client education materials and other supports/resources
 - Interventions for clients with limited health literacy, limited English language proficiency, vision impairment, physical disability, etc.



Informed Consent – FAQs

1. Informed Consent in the Classroom

Asked to screen/ observe/ include in session a student who is not on your caseload

- Consent is required prior to individualized health services
 - Screening
 - Observations
 - Group therapy
- Check what's covered in documented classroom consent
- Communicate informed consent requirements to teaching/admin staff



2. Informed Consent & Informal Guardianship

Consent for services in situations when no formal guardianship order is in place

Family member or friend looking after a child as needed without involvement from Children & Family Services or formal guardianship order;

Unable to contact legally authorized decision maker



2. Informed Consent & Informal Guardianship

- By law
 Consent must be obtained from legally authorized decision maker.
 - Current legislation on informed consent doesn't cover informal guardianship
- Check
 - What consent has already been granted for
 - Employer policy (may need to advocate for policy if this is something that comes up frequently)
 - Legal advice (counsel with expertise in family law)



3. Informed Consent to Share Information

Is consent required to share information

With another provider at my organization?

Across organizations?

Please note: Since the original presentation of this webinar, there has been a significant change in the privacy legislation reference on the next slide.

The Freedom of Information and Protection of Privacy Act (FOIP), mentioned has been repealed and replaced by:

- the 'Access to Information Act' (ATIA), and
- the 'Protection of Privacy Act' (POPA).

Both came into force on June 11, 2025.



3. Consent to Share Information

 Check the privacy legislation that applies to your setting → certain information can be shared without consent to certain receivers under the different legislation

GOA Information Sharing Decision Tree

https://www.alberta.ca/freedom-of-information-and-protection-of-privacy

Freedom of Information and Protection of Privacy Act (FOIP)

For public bodies e.g., government agencies and boards, school boards, municipalities, police

Controls the ways a **public body**may collect, use, or disclose
personal information

Health Information Act (HIA)

For custodians of health information (e.g., AHS) and their health service providers or employees

Controls the ways a **health custodian** may collect, use, or
disclose health information

Personal Information Protection Act (PIPA)

For private sector organizations e.g., private practice businesses, not-for-profit organizations, regulatory bodies

Controls the ways a **private sector organization** may collect, use, or disclose personal information

Children First Act (CFA)

For service providers and custodians for the purposes of enabling or planning the provision of services or benefits to a child

Controls to who, when, and for what purpose a child's personal health information can be released

4. Length of Informed Consent

Does informed consent have an expiry date?

Do I need to get forms re-signed every year or after a certain length of time? Should I put expiry dates on consent forms?

- If there is a date/policy about updating consent within certain timeframes → applies
- Consent should be updated whenever there is a significant change to services
 - Consent is an ongoing process, NOT a static event → updated as needed





5. Negative Consent

I haven't heard back from a parent about proceeding with an assessment – can I assume that they don't refuse consent?

Can I put on forms that consent is assumed unless I hear otherwise?

- NO!! Absence of a response should not be interpreted as consent for a service
 - There may be many reasons that a client does not get into contact – can you be sure consent is informed?



References

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Questions?

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Post-Webinar Survey: Keeping up With Informed Consent: Standards & Best Practices

