G. Disorders of Consciousness Specialty Program

Description

A Disorders of Consciousness (DoC) Specialty Program delivers services that focus on the assessment, treatment, and care of individuals with disorders of consciousness, which includes persons entering the program in a coma state, vegetative or unresponsive wakefulness state, or minimally conscious state, and potentially progressing to a post-traumatic or acute confusional state. The DoC program may be located in a hospital, skilled nursing facility, or long-term care hospital in the U.S.; acute hospital or hospital with transitional rehabilitation beds in Canada; or, in other countries, a setting that is comparably licensed.

The essential components of a DoC specialty program include the following:

- A pre-admission process facilitates entry to the DoC program through collaboration and support of acute care providers in making appropriate referrals and communication with families/support systems regarding the DoC program. Admission decisions are based on the clinical status of the person served, independent of social, psychological, or demographic characteristics.
- The team, often adopting a transdisciplinary approach, implements assessments of consciousness and interventions to increase the likelihood of emergence, reduces the impact of medical complications, and strives to optimize function and overcome challenges and obstacles to progress. Incorporating standardized, validated tools recommended for the population served and setting, a systematic assessment process provides diagnostic clarity and informs the use of evidence-based treatments to address the complex medical and rehabilitation needs of the persons served.
- Families/support systems are partners in shared decision-making and receive education and support that allow them to effectively care and advocate for their loved ones, navigate fluctuations in the clinical status of the persons served, and balance prognostic uncertainty and hope.
- Personnel receive competency-based training on the unique aspects of individuals with disorders of consciousness and ongoing support for their own well-being.
- The program advocates for the needs of persons served and their families/support systems by engaging with acute care providers and payers/funding sources regarding evidence-based standards of practice and the value of care provided by a DoC program.
- The program demonstrates the commitment, capabilities, and resources to comprehensively address the profound needs of persons with disorders of consciousness.

Applicable Standards

If an organization chooses to add the optional Disorders of Consciousness Specialty Program to a Comprehensive Integrated Inpatient Rehabilitation Program (Section 3.A.), the program description and all standards in this section are applicable.

Additionally, the standards in the following sections apply as follows:

- Sections 1.A. and 1.C.–1.M.; 1.B. Governance is optional
- Section 2.A.
- Section 2.B. (see guidelines in Section 2)
- Section 2.D. based on diagnostic categories served (see guidelines in Section 2)
- Section 2.E. if the program serves any children/adolescents and is not seeking accreditation as a Pediatric Specialty Program
- Section 2.F. if the program delivers services using information and communication technologies

4.G. **1. The program facilitates shared decision-making with families/supports systems and persons served through the following:**

a. Accessible information.

b. Timelines for exchange of information.

c. Transparent information.

d. Identification of their level of:

(1) Health literacy.

(2) Understanding of the plan of care.

Intent Statements

Refer to the Glossary for a definition of *person served.*

To facilitate the decision-making roles of the family/support system and person served, they are given information in a way that is understandable and in sufficient time to make informed decisions. Access to information reflects any cultural factors that would impact decision making.

1.c. Discussions between the DoC team and family/support systems regarding progress and prognosis of the person served are ongoing and transparent throughout the length of stay.

Examples

Decision-making is shared when providers and families/support systems work together to support the person served. Seeking input from family members/support systems is one way to work together, and providers can solicit their input by:

- Accepting and/or trying the scent, taste, or musical preferences that families/support systems and persons served may propose.
- Asking questions about the prior experiences of persons served, which supports inclusion and has the potential to create a common ground among providers and families/support systems to explore ways to help the person served respond to various stimuli.
- Offering information about what providers are doing with the person served and asking what questions families/support systems have about specific interventions or the plan of care.

1.b. The exchange of information may take place at established timeframes or during team conferences, family/support system meetings, and/or training and education sessions.

1.d.(1) Health literacy refers to the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions and services needed to prevent or treat illness.

The DoC specialty program facilitates the understanding of information by:

- Using simple language and short sentences.
- Avoiding the use of acronyms and technical language.
- Supplementing oral information with printed, audio, or video materials.
- Asking family members to summarize information they have been provided or do a return demonstration.
- Asking open-ended questions instead of yes/no questions.
- Repeating key points.
- Providing information in the primary language of the family member and person served.
- Offering assistance reviewing and completing forms.
- Using universal symbols in the physical environment.
- Ensuring that information shared by individual team members is consistent.

1.d.(2) Understanding of the plan of care may be identified through the assessment process, asking members of the family/support system to summarize discussions and decisions made in team conferences, or verification by the case manager or care coordinator.

Resources

Please refer to Appendix D for resources related to health literacy.

4.G. **2. The program demonstrates knowledge and application of evidence-based assessment and treatment practices.**

Examples

Professional associations are frequently used resources for information on evidence-based practices, clinical practice guidelines, accepted practices in the field, and peer-reviewed publications.

Team members seek specialty certifications or participate in special interest sections through their professional associations such as the International Brain injury Association, International Pediatric Brain Injury Society, or the American Congress of Rehabilitation Medicine.

Resources

Please refer to Appendix D for resources related to evidence-based practice.

4.G. **3. The program implements a written procedure that addresses preadmission:**

a. Collaboration with referral sources regarding admission of persons served to the disorders of consciousness program.

b. Communication between disorders of consciousness team members and families/support systems regarding the disorders of consciousness program.

Intent Statements

Acute care providers may have limited experience with disorders of consciousness and how to recognize and refer persons with this condition. Collaboration with referral sources regarding disorders of consciousness could include education on the recognition of these individuals and the existence of specialized programs that have the expertise to provide rehabilitation.

Examples

Communication between DoC team members and families/support systems could take place virtually or in-person and include admission criteria, scope of the DoC program, what to expect during the program, payer coverage/funding for services provided by the program, housing available for non-local family, and placement considerations upon transition/discharge from the program.

4.G. **4. The program implements a written procedure for initial and ongoing assessments that:**

a. Specifies the:

(1) Use of standardized, validated tools, as recommended for the population served and the setting.

(2) Timeframes for assessment.

(3) Frequency of assessment.

(4) Team members responsible for conducting assessments.

b. Documents for each person served, as appropriate, information about:

(1) Arousal/wakefulness.

(2) Behavioral responsiveness to commands and other stimuli.

(3) Level of consciousness.

(4) Communication.

(5) Cognition.

(6) Bladder management.

(7) Bowel management.

(8) Muscle tone/spasticity.

(9) Contracture.

(10) Dysautonomia.

(11) Nutrition.

(12) Pain.

(13) Pulmonary function.

(14) Skin integrity.

(15) Sleep/wake patterns.

(16) Swallowing.

(17) Venous thrombosis.

4.G. **5. To meet the needs of the persons served, the program provides or arranges for diagnostic services to screen for and assess the status of:**

a. Bladder function.

b. Bowel function.

c. Cardiac function.

d. Cognitive function.

e. Mental health.

f. Metabolic function.

g. **Muscoloskeletal health.**
h. **Neurologic function.**
i. **Obstetric and gynecological health.**
j. **Pulmonary function.**
k. **Sensory function.**
l. **Skin integrity.**
m. **Structural changes in the brain.**
n. **Swallowing.**
o. **Thromboembolic disease.**
p. **Other common secondary conditions.**

Note: *A comprehensive integrated inpatient rehabilitation disorders of consciousness specialty program does not have to meet Standard 7 in Section 3.A. CIIRP.*

Examples

5.e. Screening for mental health may address history of substance use, depression, trauma, etc.

5.k. Sensory screenings might address vision, hearing, tactile function/pain, and/or ability to regulate body temperature.

5.o. Thromboembolic disease could include DVT.

4.G. **6. Dependent on the needs of the persons served, level of consciousness, and identified goals, the program provides or arranges for:**

a. **Assistive technology.**
b. **Audiology services.**
c. **Chaplaincy services.**
d. **Counseling on intimacy and sexuality.**
e. **Dialysis.**
f. **Durable medical equipment.**
g. **Dysphagia management.**
h. **Environmental modification.**
i. **Medical consultative services.**
j. **Medical nutrition therapy.**
k. **Neurobehavioral services.**
l. **Neuropsychological services.**
m. **Orthotic services.**
n. **Ostomy/wound care.**
o. **Palliative care.**
p. **Peer support.**
q. **Psychological services.**
r. **Rehabilitation engineering.**
s. **Respiratory therapy.**
t. **Spasticity management.**
u. **Substance use disorder treatment.**
v. **Vestibular assessment.**
w. **Visual assessment.**

Note: *A comprehensive integrated inpatient rehabilitation disorders of consciousness specialty program does not have to meet Standard 6 in Section 3.A. CIIRP.*

4.G. **7. The program demonstrates knowledge of and coordination with local, regional, state/provincial, national, or international networks and resources to facilitate:**

a. **Specialized disorders of consciousness clinical services.**
b. **Use of appropriate subspecialties.**
c. **Advocacy.**
d. **Peer and family support.**

4.G. **8. On an ongoing basis, the program addresses the impact of a disorder of consciousness on the family/support system of the person served, including, but not limited to, the person's:**

a. **Parents.**
b. **Spouse/significant other.**
c. **Children.**
d. **Siblings.**
e. **Other members of the support system.**

Intent Statements

This standard relates to Standard 2.B.25. on assessments of the family/support system and the provision or arrangement of services to meet identified needs.

Examples

Disorders of consciousness may impact members of the family/support system in different ways. For example:

- The spouse/significant other of the person served may be experiencing anxiety or fear about current circumstances and the future, may be overwhelmed having to take on additional responsibilities related to childcare and/or household upkeep, have concerns related to finances, etc.
- Children may be upset with a parent who is unable to attend social activities, school conferences, or sports events.
- A young child may not understand why a sibling with a disorder of consciousness is not at home or cannot play the same way as before.
- Adult children involved in the care of a parent may be coping poorly with the level of support and decision making they are facing or feeling guilty about time spent away their own children.
- Parents are trying to balance the needs of their child/adolescent with a disorder of consciousness and the needs of other children and family members.
- Other members of the support system might include friends, classmates, teammates, colleagues, etc.

4.G. **9. The program provides or arranges for support, as needed, including, but not limited to:**

a. Spouse/significant other-to-spouse/significant other.

b. Parent-to-parent.

c. Family/support system-to-family/support system.

d. Sibling-to-sibling.

e. Peer-to-peer.

4.G. **10. The program provides an organized education program about disorders of consciousness that:**

a. Is appropriate to the needs of:

(1) Families/support systems.

(2) Persons served.

b. Considers the readiness of the family/support system and person served to receive the education.

c. Is reinforced:

(1) Among members of the disorders of consciousness team.

(2) Throughout the duration of the program.

d. Includes, but is not limited to:

(1) Active involvement in the service delivery process.

(2) Behavioral supports.

(3) Boundaries.

(4) Clinical aspects of disorders of consciousness, including:

(a) Diagnostic features.

(b) Prognostic indicators.

(c) Levels of consciousness.

(d) Common signs of emergence.

(5) Cognitive interventions.

(6) Communication interventions.

(7) Communication with providers.

(8) Community resources.

(9) De-escalation of care.

(10) Developmental/life transitions.

(11) Equipment use.

(12) Levels of care.

(13) Medical needs and potential complications.

(14) Nutrition.

(15) Palliative care.

(16) Pulmonary care.

(17) Self-advocacy.

(18) Self-management.

Intent Statements

10.d.(9) In accordance with local laws and regulations, de-escalation of care may be a

consideration for families/support systems that are facing end-of-life decision making for the person served.

Examples

The education program could be provided using a variety of methods such as one-on-one teaching, formal groups, and lectures; videos or audio recordings; written information; and online programs.

10.d.(9) De-escalation of care might include removal of a tracheostomy or mechanical ventilation, withdrawal of hydration and/or nutrition, withholding active medical treatments when a person served becomes ill or has established do-not-resuscitate orders, among other measures.

10.d.(17) Self-advocacy may address working with insurance companies and other funding resources.

4.G. **11. To advance the field of disorders of consciousness, the program provides information:**

a. To families/support systems.

b. To persons served.

c. About available:

(1) Clinical trials.

(2) Research opportunities.

Resources

Please refer to Appendix D for resources related to clinical trials.

4.G. **12. The program implements a process to address ethical concerns related to disorders of consciousness.**

Intent Statements

As part of an organization's ethical codes of conduct (related to Standard 1.A.6.), established ethical principles can be used as a guide for addressing complex dilemmas. Addressing concerns in a confidential and supportive manner is key as a decision or resolution of a problem is not always the desired or expected outcome of the process.

Examples

Learning circles, ethics committees, and consultations with an ethicist may be used to address ethical concerns.

Examples of ethical concerns related to DoC care include:

- Withdrawal of life-sustaining treatment.
- Parents who disagree on the use or withdrawal of life-sustaining treatment.
- A person served who does not have an advance directive and family members disagree on the use of life-sustaining measures.
- Pain management administration and the potential for hastening death.
- Changes in consent and capacity.
- Medical interventions that are non-beneficial or futile.

4.G. **13. The organization establishes a policy on de-escalation of care.**

Intent Statements

A policy establishes the organization's position on de-escalation of care so that families/support systems, persons served, personnel, and other relevant stakeholders may understand whether de-escalation of care is available, accessible, or addressed by the program, and, if so, in what way.

The organization complies with all legal and regulatory obligations related to de-escalation of care.

Examples

If de-escalation of care is legal in the jurisdiction, an organization may still consider if it is in conflict with religious, ethical, or other principles and prohibit its use or access.

If de-escalation of care is not legal in the jurisdiction, the policy indicates whether the program will assist families/persons served with information and resources on where de-escalation of care is available.

De-escalation of care is included in discussions regarding treatment options, short- and long-term prognosis, care trajectory, and burden of care at appropriate times during the length of stay.

De-escalation of care is not a decision that is required to be made in any one specific period of time during the stay.

Discussions with family members regarding prognosis, de-escalation of care, and end-of-life decision making may reference guidance such as the 2024 Best Practice Guidelines for Traumatic Brain Injury by the American College of Surgeons and the American Congress of Rehabilitation Medicine which addresses recovery timelines.

4.G. **14. The program:**

- **a. Gives opportunities for expression of final wishes concerning end-of-life to:**
  - **(1) Families/support systems.**
  - **(2) Persons served.**
- **b. Initiates related services when appropriate.**
- **c. Provides education as needed regarding end-of-life choices.**

Intent Statements

Members of the family/support system and the persons served, to the extent they are able to participate, are offered opportunities to discuss end-of-life planning.

Examples

Do-not-resuscitate orders are known and strictly adhered to.

Information is provided on advanced care planning, palliative care, and hospice as requested.

4.G. **15. The program implements a policy and written procedure that address families/support systems staying with the persons served 24 hours a day.**

Intent Statements

The program specifies in policy whether members of the family/support system may remain with the person served 24 hours a day, 7 days a week.

Examples

If the program allows members of the family/support system to stay with the person served 24/7, written procedures outline criteria for staying, how and by whom decisions are made, exceptions, whether the physical facility is conducive or can be adapted for such arrangements, and other resources such as a training apartment on campus, Ronald McDonald house, or arrangements with a nearby hotel where family members can stay.

There may be times when it is determined that staying 24/7 is not in the best interest of the person served, e.g., a family member who is exhausted, overwhelmed, has their own health concerns, or is disruptive to the service process or legal reasons such as custody issues that would prohibit a parent from staying.

4.G. **16. To promote seamless service delivery for the persons served:**

- **a. The disorders of consciousness program proactively coordinates, facilitates, and advocates for appropriate transitions.**
- **b. Discharge/transition planning addresses:**
  - **(1) Access to healthcare.**
  - **(2) Capability of the family/support system.**
  - **(3) Co-morbid conditions.**
  - **(4) Contingency plans.**
  - **(5) Current disorders of consciousness treatment interventions.**
  - **(6) The environment of the next component of the continuum of services or discharge location, including:**
    - **(a) Facilitating factors.**
    - **(b) Barriers.**
  - **(7) Expectations of the:**
    - **(a) Family/support system.**
    - **(b) Person served.**
  - **(8) Financial resources.**
  - **(9) Identification of resources in the community that are or will be involved with the person served.**

(10) The level of understanding of the family/support system regarding:
  - **(a) Level of consciousness of the person served.**
  - **(b) Functional status of the person served.**

(11) Life routines.

(12) Mechanisms for coordination with other resources.

(13) Risk of complications.

(14) Self-advocacy.

(15) Transportation.

Intent Statements

16.b. Planning may address discharge/transition to another level of services within the continuum offered by the organization or to another setting including home and/or another organization and may be geared toward maintenance and/or improvement depending upon the needs and status of the person served.

16.b.(11) Discharge/transition planning encompasses more than recommendations to meet ongoing medical and rehabilitation needs. It also incorporates those daily routines and activities that are meaningful to the person served.

Examples

16.a. The program demonstrates coordination among all components of its continuum of services and with those to which it links. This may include interaction and feedback such as formal meetings related to discharge/transition planning for individual persons served, the sharing of treatment techniques and strategies between program teams, written communications, teleconferences, and the timely transmission of records.

16.b.(2) For discharge/transition to be successful for the person served, it is critical for the family/support system to be realistic in its expectations and about its capabilities. For example, it may be important for family members to consider how respite care will be used to ease caregiver burden.

16.b.(8) The program addresses conservation of funding to meet long-term needs, eligibility for additional funding for services, and other resources such as charitable funds and public funds.

4.G. **17. The disorders of consciousness program minimizes challenges and obstacles related to:**
- **a. Family/support system dynamics.**
- **b. Discharge/transition planning.**
- **c. Continuity of care.**

Examples

17.b.–c. For the person served to make a successful transition to the next level of services or home, potential challenges and obstacles are anticipated and addressed. For example, if the discharge plan involves the person going home it is important to ensure that members of the family/support system are available and prepared to address the needs of the person served in the home environment. Or, if home adaptations are necessary they are identified and planned in advance so they can be completed by the time of discharge.

Follow-up plans are clearly communicated to all parties and appointments, arrangements, and expectations are specified and followed through. If transportation is not available, community resources to assist with transportation to appointments are provided.

4.G. **18. The disorders of consciousness program:**
- **a. Provides or arranges for follow-up care.**
- **b. Identifies a point of contact:**
  - **(1) If emergence from a disorder of consciousness is suspected, necessitating a different level of care.**
  - **(2) If there is a decline in clinical status of the person served requiring further assessment.**
  - **(3) To act as a resource to address follow-up questions and concerns.**
- **c. Establishes a plan of follow-up for each person served that provides for:**
  - **(1) Designation of the individual(s) to be responsible for coordination of the follow-up plans of the person served.**

(2) Communication of discharge recommendations.

(3) Communication of identified risks.

d. Collaborates with primary care and specialty physicians and other healthcare providers regarding the needs of the person served.

Examples

18.c.(1) Individuals responsible for coordinating the follow-up plans of the person served might be a family member, a case manager, a primary care physician, or another healthcare provider.

4.G. **19. The disorders of consciousness program implements a written procedure regarding comprehensive reviews for persons served following discharge that addresses:**

a. Time frames for the review(s).

b. Implementation of the discharge plan.

c. Current needs/concerns.

Examples

The program may offer reviews through teleconference, follow-up appointment, or calls involving the person served and members of the family/support system.

4.G. **20. To facilitate advocacy for persons served, the disorders of consciousness program demonstrates knowledge of:**

a. Regulations.

b. Legislation.

c. Funding availability.

d. Service availability.

e. Protection and advocacy resources.

f. The healthcare delivery system.

g. Resources and services related to aging.

Examples

20.a. The program stays up to date on current regulations and potential changes to regulations. The program encourages personnel, as appropriate, to respond to requests for public comment when regulatory changes are proposed. Part of the program's corporate citizenship may be to testify during regulatory reviews or development of new or revised regulations.

20.b. Many pieces of legislation are proposed in the arena of brain injury. Being active with national or state/provincial trade associations that stay current with legislative proposals is integral to a DoC specialty program.

20.c. The program is knowledgeable about how funding may or may not be provided by payers for DoC rehabilitation services, including whether written exclusions exist in insurance policies for this type of care.

20.e. The program is knowledgeable about the resources and opportunities available through disability rights organizations and networks.

Resources

Please refer to Appendix D for resources related to protection and advocacy.

4.G. **21. Within its scope of practice and expertise, the program acts as a resource to providers engaged in acute services regarding:**

a. Clinical aspects of disorders of consciousness.

b. Evidence-based assessment and treatment practices.

c. Outreach and support.

d. Advocacy for disorders of consciousness rehabilitation.

Examples

The program acts as a resource to other providers engaged in acute services who may encounter or provide care to persons with disorders of consciousness. It may provide educational sessions or materials, consultation, or training to providers on topics such as recognizing the signs and symptoms of disorders of consciousness and distinguishing it from other conditions; standardized assessment tools recommended for the population served and the setting; the development of treatment practices, service models, and programs for persons served throughout the brain injury continuum of services; respite care; peer counseling and mentoring; cognition and

behavior; appropriate service referrals; factors facilitating and barriers to achievement of optimal outcomes; collaboration with providers on the timing of interventions; and advocacy activities with payers and other funding sources.

4.G. **22. The program demonstrates advocacy efforts with payers and funding sources that address:**
- **a. Value of care provided by a disorders of consciousness program.**
- **b. Evidence-based standards of practice.**
- **c. Outcomes of the disorders of consciousness program.**

Intent Statements

See the Glossary for a definition of *value.*

Examples

When advocating with payers and funding sources and sharing information on the value of care provided, disorders of consciousness programs may share information on the outcomes of persons served/effectiveness or the efficiency of the program. Additionally, the confirmation of a valid diagnosis of disorder of consciousness and efforts to minimize complications resulting in increased costs can demonstrate the value of care provided.

4.G. **23. Documented, competency-based education and training for personnel that addresses the unique needs of persons with disorders of consciousness:**
- **a. Is provided:**
  - **(1) At orientation.**
  - **(2) On an ongoing basis.**
- **b. Includes, but is not limited to:**
  - **(1) Administration of standardized tools used for neurobehavioral assessment/assessment of consciousness.**
  - **(2) Age-specific considerations.**
  - **(3) Clinical aspects of disorders of consciousness.**
  - **(4) Communication with persons served.**
  - **(5) Communication with family members regarding prognosis of the person served.**
  - **(6) Medical considerations, including, but not limited to:**
    - **(a) Contracture management.**
    - **(b) Dysautonomia.**
    - **(c) Factors that may compromise arousal and responsiveness.**
    - **(d) Late effects of brain injury.**
    - **(e) Positioning.**
    - **(f) Sepsis.**
    - **(g) Spasticity.**
    - **(h) Tone management.**
  - **(7) Preventing medical complications.**
  - **(8) Safe patient handling.**
  - **(9) Setting team-based goals that each team member supports.**

Intent Statements

Competency-based education and training are delivered as new recommendations and guidance become available. It is not expected that all topics be addressed every year but rather that the content and focus of education and training may vary over time to reflect new developments and priorities in the field and on the part of the organization.

See the Glossary for a definition of *competency-based training*.

Examples

23.b.(9) Providers that embrace a transdisciplinary approach transcend traditional disciplinary boundaries to create shared goals for the persons served based on their collective experience and expertise.

4.G. **24. On an ongoing basis, the program supports the well-being of personnel through:**
- **a. Timely debriefings.**
- **b. Opportunities to express emotions.**
- **c. Access to resources that support personal well-being.**

Intent Statements

Depending on the size and scope of the program, opportunities are available to support well-being and minimize or counteract the compassion fatigue of personnel.

Examples

24.c. Resources might include supervisory and peer support groups or individual sessions to address challenges, share wisdom, and celebrate 'small victories;' relaxation/quiet spaces; employee assistance programs; training on coping strategies and how to manage stress; open-door and flexible workplace policies; and onsite wellness activities.