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TEMPORARY ADMINISTRATIVE ORDER
INCLUDING STATEMENT OF NEED & JUSTIFICATION

APD 19-2024
CHAPTER 411
DEPARTMENT OF HUMAN SERVICES
AGING AND PEOPLE WITH DISABILITIES AND DEVELOPMENTAL DISABILITIES

FILED
04/30/2024 2:30 PM
ARCHIVES DIVISION
SECRETARY OF STATE
& LEGISLATIVE COUNSEL

FILING CAPTION: ODDS: SB 91 (2023) Children's Extraordinary Needs Program (411-440)

EFFECTIVE DATE: 05/01/2024 THROUGH 10/27/2024

AGENCY APPROVED DATE: 04/29/2024

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NEED FOR THE RULE(S):

The Oregon Department of Human Services, Office of Developmental Disabilities Services (ODDS) needs to immediately adopt temporary rules in OAR chapter 411, division 440 about the Children's Extraordinary Needs (CEN) Program to implement SB 91 (2023). The CEN Program is subject to the Centers for Medicare and Medicaid Services' approval of ODDS' Children's Extraordinary Needs 1915(c) waiver application.

The following rules need to be immediately adopted to implement SB 91 (2023) and establish standards, responsibilities, and procedures for the CEN Program to ensure children enrolled in the CEN Program receive high quality care from their parent provider:

- OAR 411-440-0010 Statement of Purpose
- OAR 411-440-0020 Definitions and Acronyms
- OAR 411-440-0030 General Eligibility and Exits
- OAR 411-440-0040 Qualifications for Parent Providers
- OAR 411-440-0050 Service Requirements, Limitations, and Exclusions
- OAR 411-440-0060 Training Requirements
- OAR 411-440-0070 Initial Enrollments
- OAR 411-440-0080 Ongoing Enrollments
- OAR 411-440-0090 Complaints

ODDS needs to proceed by filing this temporary rulemaking action and is unable to proceed through the permanent rulemaking process because ODDS needs to immediately implement the CEN Program to meet legislative intent and begin to offer enrollment in the CEN Program to children with very high medical needs or very high behavioral needs.

JUSTIFICATION OF TEMPORARY FILING:

The rules in OAR 411, division 440 need to be immediately adopted to meet the legislative intent of SB 91 (2023) and implement the CEN Program.

Failure to act promptly and immediately adopt the rules in OAR chapter 411, division 440 prevents ODDS from implementing the CEN Program and complying with Oregon Law. This will result in serious prejudice to children with very high medical needs or very high behavioral needs, families of these children, and ODDS.

Without these rules, the CEN Program is not able to operate and ODDS is not able to begin to offer enrollment into the CEN Program to children whose medical or behavioral needs are extraordinary.

Immediately adopting the rules in OAR chapter 411, division 440 allows ODDS to establish standards, responsibilities, and procedures for the CEN Program to meet the legislative intent of SB 91 (2023) and ensure children enrolled in the CEN Program receive high quality care from their parent provider.

DOCUMENTS RELIED UPON, AND WHERE THEY ARE AVAILABLE:

1. Enrolled Senate Bill 91 (2023). Available at: https://olis.oregonlegislature.gov/liz/2023R1/Downloads/MeasureDocument/SB0091/Enrolled
2. Overview and Measure History of Senate Bill 91 (2023). Available at: https://olis.oregonlegislature.gov/liz/2023R1/Measures/Overview/SB91
3. ORS 427.191. Available at: https://www.oregonlegislature.gov/bills_laws/ors/ors427.html
4. ODDS Senate Bill 91 Implementation. Available at: https://www.oregon.gov/odhs/idd/Pages/sb-91-implementation.aspx

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RULES:
411-440-0010, 411-440-0020, 411-440-0030, 411-440-0040, 411-440-0050, 411-440-0060, 411-440-0070, 411-440-0080, 411-440-0090

ADOPT: 411-440-0010

RULE TITLE: Statement of Purpose

RULE SUMMARY: OAR 411-440-0010 about the Statement of Purpose is being immediately adopted to implement SB 91 (2023) and establish standards, responsibilities, and procedures for the CEN Program to ensure children enrolled in the CEN Program receive high quality care from their parent provider.

RULE TEXT:
(1) The rules in OAR chapter 411, division 450 establish standards, responsibilities, and procedures for the Children's Extraordinary Needs (CEN) Program to ensure eligible children enrolled in the program receive high-quality care from a parent provider that complies with applicable state and federal law.
(2) The CEN Program is for children from birth through age 17, assessed to have very high medical needs or very high behavioral needs requiring extraordinary care.
(3) Through the CEN Program, provider agencies employ parent providers to deliver no more than 20 hours of attendant care to their child each week.
(4) The intent of the CEN Program is to not displace non-parent providers. Provider agencies shall continue to recruit, train, and retain non-parent providers.
(5) The CEN Program is subject to the approval of the Children's Extraordinary Needs 1915(c) waiver application by the Centers for Medicare and Medicaid Services.

STATUTORY/OTHER AUTHORITY: ORS 409.050, 427.104, 427.191, 430.662

STATUTES/OTHER IMPLEMENTED: ORS 409.010, 427.007, 427.101, 427.104, 427.191, 430.215, 430.610, 430.662

ADOPT: 411-440-0020

RULE TITLE: Definitions and Acronyms

RULE SUMMARY: OAR 411-440-0020 about Definitions and Acronyms is being immediately adopted to implement SB 91 (2023) and establish standards, responsibilities, and procedures for the CEN Program to ensure children enrolled in the CEN Program receive high quality care from their parent provider.

RULE TEXT:

In addition to the following definitions and acronyms, OAR 411-317-0000 includes general definitions for words and terms frequently used in OAR chapter 411, division 440. If a word or term is defined differently in OAR 411-317-0000, the definition in this rule applies.

(1) "Abbreviated School Day Program" means an education program in which a school district restricts access for a student with a disability to hours of instruction or educational services to less than the number of hours of instruction or educational services provided to the majority of other students, in the same grade, within the student's resident school district, for more than 10 school days per school year.

(2) "Attendant Care" is defined in OAR 411-317-0000 and described in OAR 411-450-0060.

(3) "Children's Extraordinary Needs (CEN) Program" means the program where a parent of a child is paid by a provider agency to deliver attendant care to their child.

(4) "Child" is an individual under the age of 18.

(5) "Client Child" means a child receiving paid supports from a parent provider.

(6) "Completed Application" means the application created by the Department is filled out accurately and contains all of the information needed to add a child to the waitlist for the CEN Program.

(7) "Direct Support Professional" means a person hired, employed, trained, paid, and supervised by a provider agency to provide attendant care services to a client of the agency.

(8) "Good Cause" means an excusable mistake, surprise, excusable neglect (which may include neglect due to a significant cognitive or health issue) due to:

(a) Circumstances beyond the control of a person;

(b) Reasonable reliance on the statement of Department staff, a case management entity, or a provider agency relating to procedural requirements; or

(c) Fraud, misrepresentation, or other misconduct of the Department or party adverse to the person.

(9) "Guardian" is defined in OAR 411-317-0000.

(10) "Health Systems Division Medical Programs" is defined in OAR 410-200-0015.

(11) "Medically Fragile Model Waiver" is defined in OAR 411-300-0110.

(12) "Medically Involved Children's Waiver" is defined in OAR 411-300-0110.

(13) "Oregon Supplemental Income Program-Medical" is defined in OAR 411-317-0000.

(14) "Ownership Interest" is when a person:

(a) Has an ownership interest totaling 5 percent or more in a provider agency;

(b) Has an indirect ownership interest equal to 5 percent or more in a provider agency.

(c) Has a combination of direct and indirect ownership interests equal to 5 percent or more in a provider agency;

(d) Owns an interest of 5 percent or more in any mortgage, deed of trust, note, or other obligation secured by a disclosing entity if that interest equals at least 5 percent of the value of the property or assets of a provider agency;

(e) Is an officer or director of a provider agency;

(f) Is a partner in a provider agency that is organized as a partnership; or

(g) Is a member of the board of directors of a provider agency.

(15) "Parent" means the biological parent, adoptive parent, stepparent, or legal guardian of a child.

(16) "Parent Provider" means a parent employed by a provider agency as a direct support professional to deliver hourly attendant care to their own child.

(17) "Provider Agency" is defined in OAR 411-317-0000.

(18) "Residential Program" is defined in OAR 411-317-0000.
(19) "These Rules" mean the rules in OAR chapter 411, division 440.
(20) "Very High Behavioral Needs":
(a) Means an Oregon Needs Assessment has determined a General Support Need Score for a child and the child:
(A) Exhibits at least two behaviors identified in OAR 411-450-0060, Table 4, in the section about the Behavior Support Need Score; and
(B) Has a current Positive Behavior Support Plan, as described in OAR 411-304-0150(5), to address the behaviors identified in subsection (A) of this section.
(b) May also be known as "service group 5b" or "5b".
(21) "Very High Medical Needs":
(a) Means an Oregon Needs Assessment has determined a General Support Need Score for a child and the child requires a support person to perform a medical task identified in OAR 411-450-0060, Table 4, in the section about the Support Person Performs Score at least daily.
(b) May also be known as "service group 5m" or "5m".
(22) "Vulnerable Person" means a person who requires physical care and monitoring who is:
(a) 65 years of age or older;
(b) Financially incapable as defined in ORS 125.005;
(c) Incapacitated as defined in ORS 125.005; or
(d) A person with a disability who is susceptible to force, threat, duress, coercion, persuasion, or physical or emotional injury because of the person's physical or mental impairment.
(23) "Waitlist" means a list maintained by the Department for the purpose of determining the order of enrollment into the CEN Program when a space in the CEN Program becomes available.

STATUTORY/OTHER AUTHORITY: ORS 409.050, 427.104, 427.191, 430.662

STATUTES/OTHER IMPLEMENTED: ORS 409.010, 427.007, 427.101, 427.104, 427.191, 430.215, 430.610, 430.662

ADOPT: 411-440-0030

RULE TITLE: General Eligibility and Exits

RULE SUMMARY: OAR 411-440-0030 about General Eligibility and Exits is being immediately adopted to implement SB 91 (2023) and establish standards, responsibilities, and procedures for the CEN Program to ensure children enrolled in the CEN Program receive high quality care from their parent provider.

RULE TEXT:

(1) A child may not be denied services or otherwise discriminated against on the basis of race, color, religion, sex, gender identity, sexual orientation, national origin, marital status, age, disability, source of income, duration of Oregon residence, or other protected classes under federal and Oregon Civil Rights laws.

(2) Initial and ongoing determinations of eligibility for the CEN Program are the sole responsibility of the Department.

(3) To be eligible for the CEN Program, a child must meet the following requirements:

(a) Be an Oregon resident who meets the residency requirements in OAR 461-120-0010.

(b) Be determined eligible for developmental disabilities services by the Community Developmental Disabilities Program of the county of origin as described in OAR 411-320-0080; or be enrolled in, or on, the waitlist for the Medically Involved Children's Waiver or the Medically Fragile Model Waiver Program as described in OAR chapter 411, division 300.

(c) Be receiving a Medicaid Title XIX benefit package through OSIPM (Oregon Supplemental Income Program-Medical) or Health Systems Division medical programs.

(d) Be determined to meet a level of care as defined in OAR 411-317-0000.

(e) Be assigned to the highest service group due to their very high medical needs or very high behavioral needs according to a current, valid Oregon Needs Assessment.

(f) Not be enrolled in a residential program.

(4) A child must be exited from the CEN Program if:

(a) The child turns 18 years of age.

(b) The child no longer meets at least one of the eligibility requirements described in section (3) of this rule.

(c) Monthly case management contact by a services coordinator, as described in OAR 411-415-0090(1), is not accepted.

(d) A parent is not employed by a provider agency to provide attendant care for their minor child 90 calendar days after the child is enrolled in the CEN Program. The Department may extend this time period when the Department determines there is good cause.

(e) The parent provider does not deliver attendant care to their child for 90 consecutive days. The Department may extend this time period when the Department determines there is good cause.

(f) When a child enters a residential program, except as described in section (6) of this rule.

(5) When a child is being exited from the CEN Program because the child no longer meets the eligibility requirement described in section (3)(e) of this rule, the child may remain in the CEN Program until the end of the month following the month in which a functional needs assessment determines the child is no longer assigned to the highest service group with very high medical needs or very high behavioral needs.

(6) A child whose parent voluntarily withdraws their child from the CEN Program to enroll the child in a residential program, may return to the CEN Program until the end of the month following the month the child entered the residential program.

(7) NOTIFICATION OF PLANNED ACTION. Prior to a child exiting from the CEN Program, the Department shall provide a written advance Notification of Planned Action (form 0947) as described in OAR 411-318-0020.

(8) HEARINGS.

(a) A hearing is addressed according to ORS chapter 183 and OAR 411-318-0025.

(b) A parent may request a hearing as provided in ORS chapter 183 and OAR 411-318-0025.

STATUTORY/OTHER AUTHORITY: ORS 409.050, 427.104, 427.191, 430.662

STATUTES/OTHER IMPLEMENTED: ORS 409.010, 427.007, 427.101, 427.104, 427.191, 430.215, 430.610, 430.662

ADOPT: 411-440-0040

RULE TITLE: Qualifications for Parent Providers

RULE SUMMARY: OAR 411-440-0040 about Qualifications for Parent Providers is being immediately adopted to implement SB 91 (2023) and establish standards, responsibilities, and procedures for the CEN Program to ensure children enrolled in the CEN Program receive high quality care from their parent provider.

RULE TEXT:

(1) A parent provider must be employed by a provider agency certified in accordance with OAR chapter 411, division 323 with an endorsement to operate as either a community living supports agency or a standard model agency as defined in OAR chapter 411, division 450. A person cannot be employed by a provider agency as a parent provider if the parent or a member of the parent's family has an administrative role, leadership role, or ownership interest in the provider agency.

(2) A parent provider must meet all of the qualifications established for provider agency staff in OAR 411-323-0050(8) and any additional qualifications established by the provider agency.

(3) A parent provider must be the parent of the client child.

(4) A parent must be hired by a provider agency to be a parent provider within 90 calendar days of an offer to enroll in the CEN Program.

(5) A parent provider must deliver attendant care at least once every 90 calendar days.

STATUTORY/OTHER AUTHORITY: ORS 409.050, 427.104, 427.191, 430.662

STATUTES/OTHER IMPLEMENTED: ORS 409.010, 427.007, 427.101, 427.104, 427.191, 430.215, 430.610, 430.662

ADOPT: 411-440-0050

RULE TITLE: Service Requirements, Limitations, and Exclusions

RULE SUMMARY: OAR 411-440-0050 about Service Requirements, Limitations, and Exclusions is being immediately adopted to implement SB 91 (2023) and establish standards, responsibilities, and procedures for the CEN Program to ensure children enrolled in the CEN Program receive high quality care from their parent provider.

RULE TEXT:

(1) The Department shall only reimburse a provider agency for the delivery of attendant care described in OAR 411-450-0060(2) by a parent provider.

(2) A provider agency may not be paid using Department funds for the delivery of attendant care by a parent provider in any of the following circumstances:

(a) During a client child's assigned public school's regular instructional hours, except:

(A) When the client child is temporarily absent from school due to surgery or illness; or

(B) When a school district places the client child on an abbreviated school day program.

(b) Due to a parent's choice to have the client child attend public or private school for fewer hours than the regular instructional hours of the child's assigned public school.

(c) During homeschooling, tutoring, or as a supplement to the public, private, or homeschool education of a client child.

(d) While simultaneously caring for or supervising a child under 10 years old or a vulnerable person of any age who requires physical care and monitoring.

(e) During the course of activities not for the primary benefit of the client child, such as:

(A) Grocery shopping for the parent provider's household.

(B) Housekeeping not required for the disability-related support needs of the client child.

(C) Remote work or the operation of a home business.

(D) Transporting individuals other than the client child to activities or appointments.

(f) When any condition described in OAR 411-450-0050(8) is present.

(g) The child is 18 years old or older.

(3) A parent provider may not act as a client child's legal or designated representative in connection with the provision of Department-funded supports.

(4) A child may not be enrolled in the CEN Program while enrolled in a residential program.

(5) A child's legal or designated representative who authorizes the child's ISP is required to participate in monthly case management contact as described in OAR 411-415-0090(1).

(6) A child's legal or designated representative must permit at least two case management contacts per ISP year, separated by no fewer than 90 calendar days, to occur in person with the child.

STATUTORY/OTHER AUTHORITY: ORS 409.050, 427.104, 427.191, 430.662

STATUTES/OTHER IMPLEMENTED: ORS 409.010, 427.007, 427.101, 427.104, 427.191, 430.215, 430.610, 430.662

ADOPT: 411-440-0060

RULE TITLE: Training Requirements

RULE SUMMARY: OAR 411-440-0060 about Training Requirements is being immediately adopted to implement SB 91 (2023) and establish standards, responsibilities, and procedures for the CEN Program to ensure children enrolled in the CEN Program receive high quality care from their parent provider.

RULE TEXT:

(1) A parent provider must complete Department-approved training prior to delivering services to their child under these rules. The training must include:

(a) An overview of federal and state administrative rules regulating home and community-based services; and

(b) The impact of providing Department-funded services on parent-child relationships with respect to discipline, supervision, physical intervention, and self-determination of a client child.

(2) A client child must receive age-appropriate, accessible training, information, or materials related to self-advocacy with respect to choosing their own direct support professionals prior to being enrolled in the CEN program.

STATUTORY/OTHER AUTHORITY: ORS 409.050, 427.104, 427.191, 430.662

STATUTES/OTHER IMPLEMENTED: ORS 409.010, 427.007, 427.101, 427.104, 427.191, 430.215, 430.610, 430.662

ADOPT: 411-440-0070

RULE TITLE: Initial Enrollments

RULE SUMMARY: OAR 411-440-0070 about Initial Enrollments is being immediately adopted to implement SB 91 (2023) and establish standards, responsibilities, and procedures for the CEN Program to ensure children enrolled in the CEN Program receive high quality care from their parent provider.

RULE TEXT:

(1) The Department shall identify all children who have very high behavioral needs, very high medical needs, or on the waitlist for the Medically Fragile Model Waiver or the Medically Involved Children's Waiver as of May 2, 2024. Only these children shall be considered for initial enrollment to the CEN Program.

(2) The Department shall assign a unique five digit number to each child. The Department shall use a random generator to shuffle the five digit numbers to determine the top 155 children offered enrollment into the CEN Program and the order of the waitlist described in OAR 411-440-0080 by their randomly assigned number.

(3) The parent of a child selected for initial enrollment must affirm to the child's case management entity their decision to participate in the CEN Program no later than July 19, 2024.

(4) If a parent declines to participate in the CEN Program by July 19, 2024:

(a) The child does not retain the number assigned to them according to section (2) of this rule.

(b) The Department shall offer the parent a choice for their child to be moved to the end of the waitlist or removed from the waitlist. If the parent of the child does not indicate a choice, the child is removed from the Department's waitlist as described in OAR 411-440-0080.

(5) If a parent does not respond to the offer to participate in the CEN Program by July 19, 2024:

(a) The child does not retain the number assigned to them according to section (2) of this rule.

(b) The child will be moved to the end of the waitlist.

(6) The Department shall confirm a child selected for initial enrollment to the CEN Program meets the eligibility requirements in OAR 411-440-0030(3). If the child is determined ineligible, the Department shall provide a written advance Notification of Planned Action (form 0947) as described in OAR 411-318-0020.

(7) No child shall be enrolled to the CEN Program prior to approval by the Centers for Medicare and Medicaid Services of the Children's Extraordinary Needs 1915(c) Waiver application.

STATUTORY/OTHER AUTHORITY: ORS 409.050, 427.104, 427.191, 430.662

STATUTES/OTHER IMPLEMENTED: ORS 409.010, 427.007, 427.101, 427.104, 427.191, 430.215, 430.610, 430.662

ADOPT: 411-440-0080

RULE TITLE: Ongoing Enrollments

RULE SUMMARY: OAR 411-440-0080 about Ongoing Enrollments is being immediately adopted to implement SB 91 (2023) and establish standards, responsibilities, and procedures for the CEN Program to ensure children enrolled in the CEN Program receive high quality care from their parent provider.

RULE TEXT:

(1) The Department shall maintain a waitlist for the CEN Program if the maximum number of children allowed on the approved CEN Waiver are enrolled in the CEN Program. Children on the waitlist may access other Medicaid or General Fund services for which the child is eligible.

(2) After the initial waitlist is established as described in OAR 411-440-0070, additional applicants for the CEN Program shall be moved to the end of the waitlist based on the completed application date for the CEN Program. In the event more than one application is completed on the same date, the Department shall randomly determine their order on the waitlist. The Department will not accept an application for a child to be added to the waitlist before July 1, 2024.

(3) A child may be removed from the waitlist if:

(a) The child is enrolled in the CEN Program.

(b) The child moves out of Oregon.

(c) The parent of the child requests their removal in writing to the Department or the child's case management entity.

(d) The child is determined ineligible for services provided by the Department.

(e) The child is deceased.

(f) The child turns 18 years old.

(4) A child who is removed from the waitlist must reapply to be added to the waitlist.

(5) When a child exits the CEN Program, the Department must offer enrollment to the CEN Program to the child next on the waitlist. If the parent of the child highest on the waitlist declines or does not respond to an offer to enroll in the CEN Program, or the child does not meet the eligibility criteria for the program under these rules, access to the CEN Program must be offered to the next child on the waitlist. This process must continue until 155 children are enrolled in the CEN Program.

(6) The parent of a child selected for enrollment must affirm to the child's case management entity their decision to participate in the CEN Program no later than 60 calendar days from the date the parent was notified of the offer to enroll in the CEN Program.

(7) If a parent declines to participate in the CEN Program:

(a) The child does not retain their number on the waitlist.

(b) The Department shall offer the parent a choice to be moved to the end of the waitlist or removed from the waitlist. If the parent of the child does not indicate a choice, the child is removed from the waitlist.

(8) If a parent or does not respond to the offer to participate in the CEN Program within 60 calendar days from the date the parent was notified of the offer to enroll in the CEN Program:

(a) The child does not retain their number on the waitlist.

(b) The child is moved to the end of the waitlist.

(9) The Department shall confirm a child selected for enrollment to the CEN Program meets the eligibility requirements in OAR 411-440-0030(3). If a child is determined ineligible at the time of the offer to enroll in the CEN Program, the Department shall provide a written advance Notification of Planned Action (form 0947) as described in OAR 411-318-0020.

(10) If a child is not eligible for the CEN Program when offered enrollment:

(a) The child does not retain their number on the waitlist.

(b) The Department shall offer the parent a choice to be moved to the end of the waitlist or removed from the waitlist. If the parent of the child does not respond, the child removed from the waitlist.

STATUTORY/OTHER AUTHORITY: ORS 409.050, 427.104, 427.191, 430.662

STATUTES/OTHER IMPLEMENTED: ORS 409.010, 427.007, 427.101, 427.104, 427.191, 430.215, 430.610, 430.662

ADOPT: 411-440-0090

RULE TITLE: Complaints

RULE SUMMARY: OAR 411-440-0090 about Complaints is being immediately adopted to implement SB 91 (2023) and establish standards, responsibilities, and procedures for the CEN Program to ensure children enrolled in the CEN Program receive high quality care from their parent provider.

RULE TEXT:
(1) Complaints related to the administration of the CEN Program must be made directly to the Department and may be made orally, in writing, or by using the Department's Complaint Form (0946).
(2) A complaint shall be addressed by the Department according to OAR 411-318-0015.

STATUTORY/OTHER AUTHORITY: ORS 409.050, 427.104, 427.191, 430.662

STATUTES/OTHER IMPLEMENTED: ORS 409.010, 427.007, 427.101, 427.104, 427.191, 430.215, 430.610, 430.662