

SPAN & Family Voices-NJ comments to the NJ Division of Developmental Disabilities, Community Care Waiver Waiting List Procedures Proposed Re-adoption with Amendments: N.J.A.C. 10:46C Proposed Repeal: N.J.A.C. 10:46C-2.4 on the proposed Community Care Waiver Waiting List Procedures

November 26, 2019

Dear Carole Johnson,



My daughter Stephanie with you at ACP Star Awards

Thank you for the opportunity to comment on the proposed Community Care Waiver (CCW), now Community Care Program, Waiting List Procedures. The SPAN Parent Advocacy Network (SPAN) is New Jersey's one-stop for families of children birth to 26 across systems; our special priorities are children and families at greatest risk due to poverty, disability and special healthcare needs, discrimination based on race, ethnicity, immigrant or language status, or other special circumstances. Family Voices-NJ is the New Jersey affiliate for Family Voices, dedicated to supporting the family voice in children's healthcare. SPAN also serves as the Parent-to-Parent USA affiliate for NJ; the NJ Parent Training and Information

Center and Family to Family Health Information Center; the RAISE National Transition Parent TA Center; REACH for Transition, and NJ State Organization of the National Federation of Families for Children's Mental Health. The Family Voices Coordinator serves on the Board of the Progressive Center for Independent Living, a second SPAN staff member serves on the NJ Statewide Independent Living Council, and a third staff member sits on the State Rehabilitation Council. Thus, we are particularly concerned with ensuring that the needs of our state's diverse children and young adults with disabilities and their families are adequately addressed.

Summary

We acknowledge that the "Community Care Waiver was transferred to the Comprehensive Medicaid Waiver and renamed the Community Care Program (CCP)...and the amendments are proposed to reflect this change." We understand that when individuals reach the "Priority Waiting List, they will receive services through either the CCP or the Supports Program (SP)." We acknowledge that the CCP provides services to individuals who meet the "level of care (LOC) for an Intermediate Care Facility (ICF) for Individuals with Intellectual Disabilities and would require institutional care without the availability of CCP services." The SP serves

individuals who do “not require that institutional level of care.” We acknowledge that the “Division has substantially transitioned from funding services through a contract reimbursement system to a Medicaid fee-for-service system.” We understand that the amendments will “omit references to in home and out-of-home service” as this distinction is not relevant in the context of fee-for-service. We acknowledge that “services for individuals under the age of 21 years has transitioned to the Department of Children and Families” and the amendments must reflect this. We note that there will be an update on the definition of legal guardian and terminology used in support coordination; we strongly recommend that the state explicitly define, reference, and recommend the use of, supported decision-making as an alternative to guardianship that does not deprive individuals with disabilities of their civil rights. We also note that individuals who reach the priority level will be removed from the wait list. We understand that individuals ineligible or choosing not to enroll in the “CCP will be removed after the Division offers them enrollment in the SP, if they are not already enrolled in the SP.” We are concerned, however that the Division is already putting CCP eligible individuals on the Supports Program and think families are unaware of their options. In this case, clarification is needed if this means the individual will then never be eligible for the CCP. We understand that “Chapter 46C is set to expire on September 17, 2019” but that the “expiration date of the chapter was extended 180 days to March 15, 2020.” We appreciate that “The Department proposes to add definitions for ‘CCP’ and ‘SP,’ as these waiver programs were not in existence” and this will help families make informed decisions. We appreciate the flexibility in the definition of emergency placement that emergency services are not required to be a community placement. We are concerned with repealing criteria for “placing children and young adults on the Priority Waiting List” as DCF serves children under 21. We seek clarification if this means that the individual will be placed on the list only as an adult, making the wait longer. We support the change of guardian from “sole custody” to “acts as primary caregiver” which increases flexibility in supportive decision-making. We note that once the sole caregiver is age 55, the individual is then on the priority list, but are concerned this isn’t being implemented. We acknowledge that a formal LOC review and appeal rights exist, but this may not address those being put into SP who may be eligible yet unaware of the CCP. We appreciate that in an emergency an individual goes to the top of the priority list without waiting.

Social Impact

We agree that if the proposed rule is implemented appropriately, in general it will result in a “positive social impact.”

Economic Impact

We agree that the proposed rule, repeal, and amendments “will not affect economic impact.”

Federal Standards Statement

We understand that a “Federal standards analysis is not required.”

Jobs Impact

We acknowledge that the proposed rule “will not generate jobs.”

Agriculture Industry Impact

We understand that this proposal will “have no impact on the agriculture.”

Regulatory Flexibility Statement

We acknowledge that a “regulatory flexibility analysis is not required because the rules proposed for reoption with amendments and a repeal do not impose reporting, recordkeeping, or other compliance requirement.”

Housing Affordability Impact Analysis

We understand that this rule will have no impact on the “affordability of housing.”

Smart Growth Development Impact Analysis

We acknowledge that this proposal will “have no impact on smart growth.”

Racial and Ethnic Community Criminal Justice and Public Safety Impact

We understand that this rule “will not have an impact on pretrial detention, sentencing, probation, or parole policies concerning adults and juveniles in the State.”

CHAPTER 46C

COMMUNITY CARE [WAIVER] **PROGRAM** WAITING LIST PROCEDURES

SUBCHAPTER 1. GENERAL PROVISIONS

10:46C-1.1 Purpose

10:46C-1.2 Scope

We understand that this “chapter does not apply to similar services [, such as self Directed day habilitation,]”

10:46C-1.3 Definitions

We understand that CCP eligibility meets the “level of care for an Intermediate Care Facility.”

Although we understand that if “individual is homeless or in imminent peril and the Division cannot provide adequate alternate service” that emergency placement is an option, we seek clarification on if this includes if something happens to the primary caregiver.

Although we understand that “‘Legal guardian’ means a person or agency appointed by a court of competent jurisdiction [or otherwise legally authorized and responsible to act on behalf of a minor or incapacitated adult,” we would recommend the addition of recognition of supported decision-making in which the individual is supported but doesn’t lose all rights.

SUBCHAPTER 2. WAITING LIST PROCEDURES

10:46C-2.1 Waiting list categories

“(a) At the time of eligibility for Division services, the applicant shall be informed of the [CCW] **CCP** waiting list.

(b) (No change.)

(c) The Division shall provide individuals on the Priority Waiting List with their numerical place on the waiting list [annually] **annually.**”

However, we are deeply concerned this is not happening as DDD caseworkers are telling families “there is no wait list.”

10:46C-2.2 Procedure for adding an individual to a waiting list or changing the individual’s waiting list category

“(a) Satisfaction of one or more of the following criteria is required for assignment to the Priority Waiting List:

1. Both of the birth or adoptive parents are 55 years or older...”

Again, this is not currently happening as it should as individuals are moved to the Supports Program then not informed of the wait list or priority wait list.

2.-5. (No change.)

(b) (No change.)

“(c) The individual, legal guardian, parent, or caregiver may request a reassessment of the waiting list assignment at any time. Requests for changes in the waiting list category shall be made in writing, or by alternate means used by the individual to communicate. If the request is approved, the change shall be made effective as of the date of the written request or request by alternate means.

1. The following types of requests for changes to the individual's waiting list category shall be processed by the [regional] **Division** waiting list coordinators and will not require a [WRT] **Waiver Review Team** meeting:"

Again this is not occurring and families are unaware of the existence of the WRT.

i. Requests for the Priority Waiting List, under the following circumstances:

(1) "Both birth or adoptive parents are over the age of 55 or the birth or adoptive parent, with whom the individual resides, is over the age of 55. In this instance, the date that the younger parent or the parent with whom the individual resides turns age 55 shall be the date the individual is added to the Priority Waiting List. If the date the parent turns 55 predates eligibility for functional Division services, the [child's] **individual's** effective date on the Priority Waiting List shall be the date of Division eligibility; **or**

(2) An individual living with a person other than the birth or adoptive parents, who is providing care voluntarily and without pay, and the caregiver can no longer provide care for the individual."

Here again we are concerned that parents are told there is no wait list, let alone not being told about being a priority. We do appreciate the flexibility under #2 allowing for other primary caregivers besides parents.

10:46C-2.3 Initial notification that an individual has been reached on the Priority Waiting List for Community Care [Waiver] **Program** Services

"(a) When an individual is reached chronologically on the Priority Waiting List, the Division shall notify the individual or legal guardian in writing, or by alternate means used by the individual to communicate. In addition, [regional case management] **the Division** will contact the individual or legal guardian to further explain the process and [offer the individual a choice between receiving in-home or out-of-home services] **discuss CCP and SP services and options.**"

Although we agree with this, it is not being implemented. Families aren't notified and aren't given a choice between CCP and SP.

[1. For individuals who choose in-home services

"3. If the individual is unable to establish [CCW] CCP eligibility within six months, the individual shall be removed from the Priority Waiting List"

Again, we understand and agree with the concept but this isn't being followed by DDD.

[10:46C-2.4 Children for whom services are requested

“(a) The Division shall assign any child placed residentially by a New Jersey Local Education Authority (LEA) to the Priority Waiting List. Placement on the list shall be based on the date that the child was residentially placed by the LEA, or no less than three years before the child’s educational entitlement ends, whichever date is earlier. “

Although we understand and agree with this idea, we find that school districts are unaware of DDD services in general so more must be done in this area.

(b) “The Division shall assign any child residentially placed by the Division of Youth and Family Services (DYFS) ...”

Again, we agree but this is outdated terminology and should be replaced with DCP&P (Division of Child Protection & Permanency).

10:46C-[2.5]2.4 Removal from the Priority Waiting List

(a) “When an individual begins receiving [CCW] CCP services and has complied with the Division’s requirement of applying for the [CCW] CCP and meeting all requirements of eligibility for those benefits, the individual’s name shall be removed from the Priority Waiting List.

(b) If, upon being reached on the Priority Waiting List, an individual or legal guardian refuses any and all offers for [CCW] CCP services, the individual’s name shall be removed from the Priority Waiting List. The Division shall provide written notification...”

We understand and agree that the individual can be removed from the Priority Waiting List under these circumstances. However, families are not refusing and in fact are unaware of the CCP services and DDD is not sending written notices to many families.

(d) “If, upon being reached on the Priority Waiting List, the individual does not elect to enroll in the CCP, or is not otherwise eligible for CCP services, the Division will offer the individual the option to elect enrollment in the Supports Program, if the individual is not already enrolled in SP, and the individual’s name shall be removed from the Priority Waiting List. The Division shall provide the individual, or his or her guardian, with written notification ...”

We cannot reiterate enough that not all families are not being given this choice and that many families have not received written notification. We also seek clarification on the process involving MLTSS (managed long-term supports and services) as some families are on MLTSS then moved to SP or CCP. We also note that there is an additional category of Supports Plus PDN (private duty nursing) which allows flexibility in assisting NJ individuals with disabilities

and their families. We seek clarification on how this dovetails with CCP, as it isn't mentioned in the amendments.

Thank you again for the opportunity to comment on the CCW (now CCP) Waiting List Procedures.

Sincerely,



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To empower families and inform and involve professionals and other individuals interested in the healthy development and education of children, to enable all children to become fully participating and contributing members of our communities and society.