

Disability Rights Network of Pennsylvania

A merger of DRNPA and the Disabilities Law Project

Protecting and Advancing the Rights of People with Disabilities

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2878

November 18, 2010

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DPW/OMHSAS
233 Beechmont Building
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PO Box 2675
Harrisburg, PA 17105-2675

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RE: Regulation #14-522; IRRC #2878
55 PA Code Chapter 23 Residential Treatment Facilities

Dear Ms. Erhard:

The Disability Rights Network of Pennsylvania (DRN) is the non-profit agency responsible for providing protection and advocacy services to Commonwealth residents with disabilities. As the state-designated Protection and Advocacy (P&A) system, DRN has federal statutory authority and duty under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and the Protection and Advocacy for Individuals with Mental Illness Act (PAIMI) to investigate incidents of abuse and neglect of individuals with disabilities and to protect their rights under federal and state laws. We write today in the strongest possible terms of support for proposed regulations *55 PA Code Chapter 23, Residential Treatment Facilities*.

In our role as the state's P&A, DRN receives and reviews hundreds of serious occurrence reports from residential treatment facilities annually. Each year we monitor numerous residential facilities, interview hundreds of residents, survey parents, and respond to complaints of alleged abuse, neglect and rights violations. We receive hundreds of calls from parents and interested others who are vitally concerned with the quality of care delivered in residential treatment facilities and respond to their requests for information, referrals, and technical assistance. It is this substantial underpinning of experience that defines DRN's uniquely qualified position to offer comments to the proposed regulations.

We note at the outset that the process OMHSAS has employed in developing the regulations has been open, inclusive, and responsive. The substance of the draft reflects a culmination of a ten year effort that encompassed the dialogue and consensus reached through stakeholder groups that included the OMHSAS Children's Advisory Committee, the Alternatives to Coercive Techniques Workgroup, and the Continuum of Care Workgroup, to name just a few. Participants in the process have included representatives of families, youth, advocacy organizations, providers, behavioral health managed care organizations, dependency and delinquency systems, and county and state officials.

There is no question of the necessity for the regulations. RTF services have long been addressed through application of *55 PA Code Chapter 3800, Child Residential and Day Treatment Facilities*. While these regulations may serve the needs of youth residing in other types of settings, they have fallen short of defining the service delivery required of providers for those youth who have the most complex behavioral health needs and for whom a much higher standard of care is essential and required by federal law.

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Though there is much to be commended in the proposed regulations, we take this opportunity to highlight a few of the most essential provisions:

§23.14 provides for a maximum capacity of 4 units of 12 beds each for a total of 48 beds. Given Pennsylvania's longstanding expressed commitment to reducing unnecessary institutionalization of individuals, it is imperative that we evolve from exceedingly large, isolated facilities that offer extremely limited access to community resources and life, reduced opportunity to interact with non-disabled peers, and little hope of access to the benefits of public schools. As the Supreme Court ruled in *Olmstead*, such institutional placement "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." Though permitting a census of 48 youth falls short of our desired goal of full community participation in homelike settings, it is an affirmative step in the right direction.

§23.17, Reportable incidents expands the definition of occurrences currently outlined under the 55 PA Code Chapter 3800 regulations to include (a)(9), use of a drug as a restraint. This is an essential protection against unintended consequences of physical restraint reduction and misuse of medication. Provision (c), requiring that reportable incident reports be forwarded to DRN and the Family Advocate, offers a needed additional layer of protection for vulnerable youth by informing independent entities that can monitor the frequency of serious occurrences and respond as needed. Provision (k), requiring that an RTF shall notify the child's parent or guardian of a restraint as soon as possible after the initiation of each emergency safety intervention, ensures that, during the most difficult of times, there will be continued connectivity with families, who can very often offer suggestions and insights into challenging behaviors, thereby reducing the likelihood of future occurrences.

§23.32, Specific Rights, includes provision (p) which enumerates the right of a child to ask staff questions related to his or her treatment; to advocate for himself or herself; to disagree respectfully; and to submit a formal grievance without jeopardizing his or her standing or privileges within the RTF. Ensuring these rights within a safe and supportive environment provides an opportunity for youth to develop self-advocacy skills, an essential component of self-determination. Youth who have self-determination skills have a stronger chance of being successful in making the transition to adulthood, including employment and independence. (Wehmeyer & Schwartz, 1997)

The Family Participation sections, §§23.41-23.44, reflect the work and consensus of a group of diverse stakeholders, including families and youth, that framed the current bulletin on this topic, *Best Practice Guidelines for Family Involvement with Youth who are in Residential Treatment Facilities*. These particular provisions build on principles of family-focused services: "Family is the core of a child's life. When shifting a child's behavior and treating serious mental health issues, the family should be engaged in the process to assure that changes are both realistic in the context of the family and the family has the skills, support, and expertise to help sustain the changes."¹

The regulations §§23.51-23.62 address staffing by requiring enhanced credentials, increased staffing ratios and more clinically oriented training topics than current Chapter 3800 requirements. Particularly commendable is §23.60, Family advocacy, which would require a full-time equivalent family advocate for 48 youth in residence. This would ensure efforts to actively engage and support families in identifying and accessing the supports and services needed to support long-term positive outcomes for

¹ Brock, L., Burrell, J., & Tulipano, T. (2006). NDTAC Issue Brief: Family involvement. Washington, DC: American Institutes for Research, National Evaluation and Technical Assistance Center for the Education of Children and Youth Who Are Neglected, Delinquent, or At Risk. http://www.neglecteddelinquent.org/nd/docs/NDTAC_issuebrief_family.pdf

the family. Equally important, as reflected in the enumerated responsibilities, this person would serve a critical quality improvement role by monitoring restraint reduction activities, grievances, observation of child rights, and facility conditions.

Restrictive Procedures, §§23.201-23.206, judiciously reflect the Commonwealth's laudable goal of restraint elimination through an emphasis on prevention through de-escalation and continuous facility-wide planning for restrictive procedures reduction. The rightful ban on deadly prone restraints has heretofore been enforced by policy interpreting current regulations (which prohibit restraints that apply pressure on a child's respiratory system) and was previously affirmed by the IRRC in 22 PA Code Chapter 14, Special Education Services and Programs, as being in the best interest of youth.

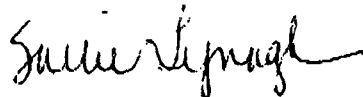
Services, §§23.221-23.230, seek to ensure that a particular provider be sufficiently equipped to meet the unique needs of the youth it intends to serve (thereby improving outcomes and reducing lengths of stay) and that, on a broader scale, the RTF array across the state be continuously responsive to emerging patterns of clinical need and evolving best practice. Of particular significance to DRN is §23.229, Education, as we have been long concerned with excessively restrictive, usually on-site, educational placements that are often assumed when a child enters an RTF. In many facilities, not a single child is attending the local public school, consequentially suffering the loss of access to an array of curricular and extra-curricular offerings that would support their immediate and long-term outcomes. Some schools have contended that this is due to a lack of information or communication from the RTF provider, and some providers have asserted that the local school district will not permit admission of the youth. This provision ensures that needed dialogue occurs between the two entities at the outset and that school districts acknowledge that which is already required of them by federal and state law, specifically, that the LEA will meet the education, special education, and related service needs of these children in the least restrictive environment.

The proposed regulations also seek to amend Chapter 5310. Community Residential Rehabilitation Services for the Mentally Ill, by enabling the establishment and licensure of small, community-based group homes for youth. It is DRN's experience, based on intake calls, review of Integrated County Service Plans, and interviews with staff, youth, and families, that many youth, particularly those who cannot return home, are unnecessarily institutionalized in RTFs due to a lack of community-based housing options. This provision would provide an avenue of relief for youth whose right to services in the most integrated setting appropriate to their needs must be realized in practice, and not just theory.

Finally, we have attached some suggested revisions that we believe would enhance, not contradict, the intent or substance of the proposed regulations that, in their current form, essentially serve the interests of the intended beneficiaries and the rightfully prioritized safety, well-being, and recovery of youth.

We greatly appreciate this opportunity to offer input on proposed 55 PA Code Chapter 23 and would be happy to provide the DPW/OMHSAS and the IRRC with any other information that might be useful.

Sincerely,



Sallie Lynagh
Children's Team Leader

**DRN COMMENTS TO TITLE 55. PUBLIC WELFARE
PART I. DEPARTMENT OF PUBLIC WELFARE
Subpart C. Licensing/Approval
Chapter 23. RESIDENTIAL TREATMENT FACILITIES**

Pg 12 -- § 23.3 Definitions. We believe that, in addition to family members, adults who were once recipients of child behavioral health services should be eligible to serve as Family Advocates. To that end, we suggest inserting "former recipient of or a" at the beginning of the definition of Family advocate:

Family advocate- A former recipient of or a family member of a child who is currently receiving services or has received services from a child-serving system including mental health, intellectual disabilities, child welfare, juvenile justice, drug and alcohol, or special education.

Pg 14 -- § 23.3 Definitions In the interest of clarity and consistency with §23.204(d), DRN suggests use of the 42 CFR §483.352 definition of seclusion with a slight modification as follows:

Seclusion-The involuntary confinement of a resident in a room or an area from which the resident is physically prevented, by either person or structure, from leaving. Examples include [P]lacing a child in a locked room, which includes a room with any type of door-locking device, such as a key lock, spring lock, bolt lock, food pressure lock or physically holding the door shut.

Pg 16 -- § 23.12(a) "lease" should be "least"

Pg 19 -- § 23.17(a)(9) Reportable incidents. Because this section requires the reporting of other prohibited acts, including such items as violations of a child's rights and sexual assault of a child, we recommend that it also require the reporting of unlawful restrictive procedures --specifically, prone and mechanical restraints.

(9) Use of a drug as a restraint[.], prone restraints, and mechanical restraints.

Pg 20 -- § 23.17(c) Consistent with language in DRN's enabling federal laws and regulations and elsewhere within these proposed regulations, change "Disability Rights Network" to "State-designated Protection and Advocacy system."

Pg 21 -- § 23.17 (i) and (k) In the interest of family involvement and maintaining and enhancing family relationships with the child, we believe that the child or youth should be given the opportunity to participate in the notifications to families of reportable incidents and restrictive procedures. To both provisions, add a sentence which reads: When circumstances permit, the child must be given the opportunity to participate in this notification.

Pg 29 -- § 23.32 (a). We submit that specific rights against discrimination be inclusive of gender identity as youth who experience discrimination or exploitation because of their sexual and/or gender identity are often put at higher risk of depression and suicide.

Pg 29 -- § 23.32 (d). It is essential that children living in RTFs are not only informed of the rules, but understand them, as adherence often impacts length of stay, privileges, and program participation. We ask that language be added that ensures comprehension:

(d) A child shall be informed of the rules of the RTF[,] in writing and orally in a language that the child understands, and American Sign Language as needed. When necessary, the RTF shall provide interpreters or translators.

Pg 30 -- § 23.32 (o). For reasons stated above, we suggest adding identity:

(o) A child shall have clean seasonal clothing that is age and gender identity appropriate.

Pg 32 -- §23.34(d) insert "policy" after "restraint"

Pg 32 -- § 23.34(e) change Disabilities Rights Network to "State-designated Protection and Advocacy system," for purposes of consistency throughout the regulations.

Pg 41 -- § 23.61(a) In order to reduce incidence of peer aggression and victimization, DRN recommends that observational checks of children in shared rooms should occur every seven minutes. The regulation would read as follows:

(a) AN RTF shall ensure that a child is supervised during awake and sleeping hours by conducting observational checks of each child at least every 15 minutes[.] for single rooms and 7 minutes for shared rooms.

Pg 48 -- § 23.82 Because of the frequency with which children are reported to have ingested cleaning products, we recommend adding a provision (d):

(d) Child use of household cleaning supplies must be directly supervised by staff.

Pg 50 -- § 23.89 (c). We suggest a slight rephrasing to add clarity:

(c) [When indoor temperature exceeds 90°F, m]Mechanical ventilation such as fans or air conditioning shall be used[.] to ensure that indoor temperature does not exceed 90°F.

Pg 52 -- § 23.102 (g)(3) Insert "covered or enclosed" as follows:

A covered or enclosed storage area for clothing.

Pg 53 -- § 23.102 (g). We recommend adding a provision (4)

(4) Should include a desk or solid writing surface.

Pg 71 -- §23.163. Regarding food groups and alternative diets, provision (b) should acknowledge vegan diets as follows:

(b) Dietary alternatives shall be available for a child who has special health needs, including a need to lower BMI, religious beliefs regarding dietary restrictions or vegetarian or vegan preferences.

Pg. 73 – § 23.183 (c). Insert “informed” and change “form” to “from” as follows:

(c) The prescribing physician shall obtain and document informed consent f[~~o~~]rom the responsible party for medication prescribed, explaining the medication's expected effects, expected side effects, and the expected effects of withholding the medication. The responsible party is the individual who initially consented for child's treatment, including the child 14 years of age and older, the child's parent or, when applicable, the child's guardian or custodian.

Pg 73 – § 23.183 (f). We believe that increases in medication dosages should be with the consent of the responsible party; however reductions, especially in cases of adverse effects, should not need to await consent. Replace “changes” with reductions:

Dosage [~~changes~~] reductions do not require additional consent; however, an RTF shall notify, by phone or in writing, the child's parents and, when applicable, the child's guardian or custodian, whenever dosage [~~changes~~] reductions are made.

Pg 78 -- § 23.201(c). For purposes of consistency with §23.201(b) insert “timeout,” before “drugs used as a restraint” and end sentence after manual restraint. Insert “Drugs used as a restraint and manual restraint” as beginning of new sentence. The provision would read as follows:

The only restrictive procedures permitted in an RTF are timeout, drugs used as a restraint and manual restraint. [~~and those~~] Drugs used as a restraint and manual restraint may be used only in an emergency safety situation in accordance with the provisions of this chapter. If a child objects...”

Pg 82 -- § 23.205(c)(2) Insert “intrusive” after “less” and before “than” so the provision reads as follows:

9(c) After every attempt has been made to anticipate and de-escalate the behavior using methods of intervention less intrusive than restraint.

Pg 88 -- § 23.205(l)(1) regarding notifications to parents of restraints. As stated previously, it is essential that the willing child, whose immediate circumstances are not prohibitive, be given the option to participate:

(1) An RTF shall notify a parent and, when applicable, the guardian or custodian, of a child who has been restrained as soon as possible, but no later than 5 hours after the initiation of the restraint. When circumstances permit, the child must be given the opportunity to participate in this notification.

Pg. 90 -- § 23.205 (k) Post-Intervention debriefings. Regarding provision (2), we believe that supervisory and administrative staff should participate in the debriefing in which the child is present. In (3), we suggest added clarity:

(2) Within 24 hours after the restraint is discontinued, staff involved in the restraint, except when the presence of particular staff may jeopardize the well-being of the child, and appropriate supervisory and administrative staff, shall meet face-to-face with the child to discuss the circumstances that resulted in the use of restraint and strategies to be used by the staff, the child, or others that could prevent the use of restraint in the future.

(3) Within 24 hours after the restraint is discontinued, and after the meeting in (2), staff involved in the restraint, appropriate supervisory and administrative staff, and the RTF Family Advocate shall conduct a debriefing session that includes, at a minimum, a review and discussion of the following

Pg 93 -- § 23.221(b)(4). In order to comply with most integrated setting requirements of the ADA, Section 504, and IDEA, RTFs need to plan for service delivery in off-site locations, most especially public schools. To that end, we recommend the phrase "including those to be provided to children attending public schools" so the provision reads as follows:

(4) The scope and a general description of the services provided by the RTF[.], including those to be provided to children attending public schools.

Pg 93 -- § 23.221(b)(6). It is essential that the service description requirements provide for an RTFs address of particular needs of transition age youth in preparation for adult life. We recommend adding to (6) "including those supporting preparation for adult life, including voting, job readiness, vocational training, and personal finance."

(6) Specific activities and programs provided by the RTF[.], including those supporting preparation for adult life, including voting, job readiness, vocational training, and personal finance.

Pg 94 -- §23.221(b)(9) should include closing parents at ASD: (ASD)

Pg. 94 -- §23.221 (b)(11): Strike as unnecessary "of the school district" so the provision reads as follows: "Verification from the LEA in which the RTF is located stating the following:"

Pg 95 -- §23.221 (b)(11)(i). For purposes of consistency with federal education laws change "most integrated setting" to "least restrictive environment" as follows: (i) The RTF has consulted with the LEA and the LEA has acknowledged its obligation to educate a child who is in an RTF in the [most integrated setting] least restrictive environment in the public school, whenever appropriate,

Pg 95 -- §23.221 (b)(11) Because the LEA's requirements are outlined in federal and state laws, they will not be effected by RTF changes. In keeping with the intent of this provision, however, we recommend deleting "requirement to provide" and inserting "provision of" as follows:

(iii) AN RTF shall notify the LEA if the RTF plans to expand or make other changes that will impact the LEA's [requirement to provide] provision of educational services.

Pg 95 -- §23.221 (b). In many RTFs, there has been an assumption upon admission that a child will attend the on-site school, even when the child is able and desires to attend the local public school, and in spite of federal and state laws mandating the child's education in the least restrictive environment. In response to this widespread problem, we strongly advocate the addition of provision (12):

(12) An acknowledgment that admission to and continued stay at the RTF is not conditioned upon the child's attendance at a particular school.

Pg 97 -- § 23.223(c)(3). Change "A person" to Person(s).

Pg 99 -- §23.223(g). Development of the ISP. To support full participation of children and families in the ISP process and to ensure their views are considered, DRN recommends adding language which provides the opportunity for documentation of disagreement as follows:

(g) Persons who participated in the development of the ISP shall sign and date the ISP, with the exception of the child, the child's parent and, when applicable, the child's guardian or custodian, who shall be given the opportunity to, but are not required to, sign the ISP. Disagreement with the ISP or refusal to sign the ISP shall be documented in the child's record. The child, the child's parent and, when applicable, the child's guardian or custodian who disagrees with the ISP may submit a written statement explaining the disagreement which shall be attached to the ISP.

Pg. 100 -- § 23.224. Content of the ISP. As stated previously, in deference to federal and state requirements, RTFs must plan for the delivery of service in public school settings when appropriate. We recommend adding the phrase "with consideration to the educational placement as determined by the LEA and parent":

(v) An explanation of the appropriate settings and time allocations for an intervention, with consideration to the educational placement as determined by the LEA and parent.

Pg 101 -- § 23.224(7). Add "goals":

(7) A component addressing how a child's education needs and goals will be met in accordance with applicable Federal and State laws and regulations.

Pg 103 -- § 23.228(b)(2). Strike as unnecessary "alternative approaches must be used" at the end of the sentence so the provision reads as follows: "Alternative approaches for a child when individual or group psychotherapy modalities are not considered effective treatment approaches, such as with a child with ASD.

Pg 103 -- § 23.228(b)(3). "hop" should be "hope."

Pg 104 -- § 23.229(a). So that the statute enabling attendance at public schools is also cited, insert "24 P.S. § 13-1306 (relating to Non-resident inmates of children's institutions) and" and "the public schools of the district," so the provision reads as follows:

Under 24 P.S. § 13-1306 (relating to Non-resident inmates of children's institutions) and 22 Pa.Code Chapters 11, 14 and 15 (relating to student attendance; special education services and programs; and protected handicapped students), a child who is of compulsory school age shall participate in the public schools of the district, a school program approved by the Department of Education, or an educational program under contract with the LEA."

Pg 104 -- § 23.229(b). To resolve widespread confusion as to which parties make final decisions regarding educational placements of children, we recommend inserting "by the LEA and parent" as follows:

(b) The decision regarding the education portion of a child's day is to be made by the LEA and parent on an individualized basis utilizing the most integrated setting, with input from members of the ISPT, local public education officials and the child's home school district.

Pg 107 -- § 23.243. Contend of child records. In this title, "Contend" should be "content."

Pg 110 -- § 23.255(b).

(b) Soiled linen shall be covered while being transported [through food preparation and food storage areas] throughout the facility.

DRN COMMENTS TO CHAPTER 5310. COMMUNITY RESIDENTIAL REHABILITATION SERVICES FOR THE MENTALLY ILL

Pg 166. Consistent with the stated Purpose of the Regulation at bottom of page 1 and continuing at top of page 2, include § 5310.6. Definitions Full-care CRRS for children, and amend by inserting "non-campus" and "for eight or less children" as follows:

§ 5310.6. Definitions Full-care CRRS for children—A non-campus program for eight or less children providing living accommodations with maximum supervision, personal assistance and a full range of psycho-social rehabilitation services for psychiatrically disabled children who display severe interpersonal adjustment problems and who require an intensive, structured living situation.

Pg. 166. Consistent with the intent of the regulation, include § 5310.92. Applicability and amend (a) by inserting "and group home" as follows:

§ 5310.92 (a) This subchapter applies to all CRRS that provide full-care for children in host home and group home settings. Persons under 18 years of age, with the exception of emancipated minors, may not be cared for in a partial-care CRRS nor in a CRRS site in which adults are served.