



DISABILITIES LAW PROGRAM

COMMUNITY LEGAL AID SOCIETY, INC.

100 W. 10th Street, Suite 801
Wilmington, Delaware 19801
(302) 575-0660 TTY (302) 575-0696 Fax (302) 575-0840
www.declasi.org

MEMORANDUM

To: SCPD Policy & Law Committee
From: Brian J. Hartman
Re: Recent Legislative & Regulatory Initiatives
Date: May 9, 2016

Consistent with the requests of the SCPD, DDC, and GACEC, I am providing an analysis of seventeen (17) legislative and regulatory initiatives. Given time constraints, the analyses should be considered preliminary and non-exhaustive.

1. DFS Final Child Protection Registry Check Reg. [19 DE Reg. 1025 (5/1/16)]

The SCPD and GACEC commented on the proposed version of this regulation in March, 2016. A copy of the March 29 memo from the SCPD is attached for facilitated reference. The Division of Family Services is now adopting a final regulation incorporating edits based on each recommendation.

First, the Councils noted that the regulation omitted coverage of student teachers. The Division added two definitions to address the omission.

Second, the Councils noted that the statute required submission of the results of the child protection registry check to the applicant for employment. The Division amended the regulation to ensure notification of the results to the applicant.

Third, the Councils identified an inconsistency between two regulations. The Division deleted one of the regulations to obviate the inconsistency.

Since the regulation is final, and DFS adopted revisions responsive to each Council comment, a "thank you" communication may be in order.

2. DFS Final Criminal History Check of Child Care Person Reg. [19 DE Reg. 1023 (5/1/16)]

The SCPD and GACEC commented on the proposed version of this regulation in March. A copy of the March 29, 2016 SCPD memo is attached for facilitated reference. The Division of Family Services is now adopting a final regulation which incorporates several amendments prompted by the commentary.

First, the Councils recommended reconsideration of use of the term “employee” to cover a host of persons who did not qualify under a common sense meaning of the term. The Councils recognized that this approach was adopted in the enabling statute but it was counterintuitive and confusing. In response, the Division revised some inconsistent references.

Second, the Councils noted that the regulation sometimes referred to “employment” as distinct from volunteering or serving as a respite provider, foster parent, or adoptive parent. The Division modified the references.

Third, the Councils noted that the title of the regulation still referred to “child care persons”. DFS amended the title to conform to statute.

Since the regulation is final, and the Division incorporated several amendments prompted by the commentary, a “thank you” communication may be in order.

3. DOE Final District/School Emergency Prep Policy Reg. [19 DE Reg. 1014 (5/1/16)]

The SCPD and GACEC commented on the proposed version of this regulation in March, 2016. A copy of the SCPD’s March 29 letter is attached for facilitated reference.

The Councils endorsed the repeal of the regulation given enactment of State legislation making DHSS primarily responsible for emergency preparedness in public schools. However, the Council also requested the status of any regulations authorized to be developed “in consultation with the Department of Education” and the latest progress report on the status of implementation of the Omnibus School Safety Act (OSSA).

The Department of Education has now acknowledged the endorsements and repealed the regulation. It is unclear if the SCPD received the update on the regulations and the status report. If they were not received, the SCPD may wish to follow up.

4. DOE Final Parent Councils Regulation [19 DE Reg. 1015 (5/1/16)]

The SCPD and GACEC commented on the proposed version of this regulation in February, 2016. A copy of the February 22 SCPD letter is attached for facilitated reference. The Department of Education is now adopting a final regulation incorporating one (1) revision prompted by the commentary.

First, the Councils recommended substituting “child with a disability” for “child with disabilities” to conform to statute. The DOE agreed and effected the revision.

Second, the Councils recommended substituting “in September of each year” for “on an annual basis”. The DOE declined to adopt the amendment.

Third, the Councils recommended insertion of some illustrations of forms of support to facilitate establishment and operation of parent councils. The DOE declined to adopt the amendment.

Since the regulation is final, and the DOE addressed each Council comment, I recommend no further action.

5. DOE Final Charter School Staff Training Reg. [19 DE Reg. 1017 (5/1/16)]

The SCPD and GACEC commented on the proposed version of this regulation in February, 2016. A copy of the SCPD's February 22, 2016 letter is attached for facilitated reference. The Councils shared only one observation on the proposed regulation, i.e, the timing of the planned training.

The Department is now adopting a final regulation which conforms to the proposed version. The DOE also clarified that training occurred in September and October of 2015 and January of 2016.

Since the regulation is final, and the DOE supplied the actual training dates, no further action is warranted.

6. DOE Final Meeting Minutes & Prior Notice Reg. [19 DE Reg. 1018 (5/1/16)]

The SCPD and GACEC commented on the proposed version of this regulation in February, 2016. A copy of the February 22 SCPD letter is attached for facilitated reference.

Meeting Minutes

First, the Councils noted that limiting a parent's right to take minutes to meetings concerning a FACE was "under inclusive" given a broader authorization under State law and another DOE regulation. The DOE effected no change. I continue to believe the regulation is not consistent with the statute and other regulation.

Second, the Councils recommended that the DOE require that parents be offered a "free" copy of minutes and that the parents have a choice of a "paper" or digital copy. The DOE inserted the word "free" but limited the copy to a digital version.

Prior Notice

First, the Councils noted that state law requires a notice to include "a full, written explanation of all the procedural safeguards available to parents under state or federal law or regulations". The DOE proposed to delete the regulation which mirrored this statute and simply say a "summary" must be "available". The DOE declined to retain the current compliant regulation. This is very unfortunate since parents will not be given an explanation of their rights prior to a meeting to help them prepare. Under the new DOE regulation, the rights could be shared at the end of the meeting, a highly disfavored approach.

Second, the Councils observed that only imposing notice requirements on IEP teams was inconsistent with statutory law which required "agencies" to issue conforming notices. There may be district and charter school notices issued by entities other than an IEP team. The DOE declined to "fix" the problem.

Third, the Councils recommended inserting three statutory references at the end of §3.0. The DOE agreed and inserted the references.

The State councils may wish to consider requesting a copy of the comments submitted by the Attorney General's Office (at 1018) and, after review, considering whether to request an Attorney General's opinion on the compatibility of the regulations with statutory law.

7. DOE Revised Prop. IEP Regulation [19 DE Reg. 969 (5/1/16)]

The Department of Education issued an initial proposed regulation amending its IEP standards in February, 2016. The SCPD and GACEC commented on that initiative. See attached February 22 SCPD letter. Instead of issuing a final regulation, the DOE is now publishing a revised proposed regulation which covers additional standards.

I have the following observations.

First, the DOE incorporates edits verbatim based on the "First" and "Third" recommendations in the SCPD's February 22 letter.

Second, in its February 22 letter, the SCPD identified a "disconnect" between §22.2.3 and State statute, 14 Del.C. §3134(1). The DOE permits "offering" (but not automatically providing) a copy of procedural safeguards at the conclusion of an IEP meeting. The statute contemplates provision of the procedural safeguards with the notice (§3134(1)). The DOE views a "notice of meeting" as not covered by §3134(1). At 969. This makes little sense. Even if arguably permitted under federal law, State law can exceed minimum federal standards. Consider the following:

A. Section 3134(8) contemplates a norm of schools providing a copy of the proposed IEP with the notice. This ostensibly represents a proposal to change a student's FACE and Section 3133 therefore requires issuance of a §3134-compliant notice, i.e., one which includes "a full explanation of all of the procedural safeguards available to the parents under state and federal law and regulations."

B. If the compliant notice is not provided prior to the meeting, the parent will not be aware of sources of legal and other assistance (e.g. DLP; PIC) [§3134(6)]; recent test and evaluation results [§3134(3)]; and other factors underlying the proposed changes to the IEP [§3134(4)].

C. Providing information about rights at the conclusion of an IEP meeting, rather than prior to the meeting, undermines effective parental participation. It is inherently a dysfunctional approach to promoting informed parental participation in the meeting.

I recommend sharing the above observations with the DOE, SBE, and Attorney General.

8. DOE Prop. School Nurse Regulation [19 DE Reg. 979 (5/1/16)]

The Department of Education proposes to adopt some discrete revisions to its school nurse standards. The rationale is as follows: "This regulation requires some formatting changes to conform to other Standard Certificates and the updating of certification requirements." At 979.

I had only one observation. The DOE may wish to reconsider §6.2. That section requires public schools to be responsible “for verifying that the School Nurse continues to meet the requirements” in certain subsections. The reference to §4.1.1 seems inapt since a nurse will not “lose” a degree. On the other hand, it may be logical to include a reference to §4.1.4 since the 90 hours of mandatory training would occur subsequent to hiring. Therefore, the DOE could consider substituting “subsections 4.1.2 through 4.1.4” for “subsections 4.1.1 through 4.1.3” in §6.2.

The Councils may wish to share the above observations with the DOE and SBE.

9. DOE Prop. “Emotional Disability” Regulation [19 DE Reg. 967 (5/1/16)]

The Department of Education proposes to adopt a discrete change to the “definitions” section of its IDEA regulations. In a nutshell, it is substituting “emotional disability” for “emotional disturbance”. At 968-969. No rationale is provided.

The current reference to “emotional disturbance” is based on the federal IDEA regulation, 34 C.F.R. §300.8. In adopting regulations in 2006, the U.S. Department of Education provided some background on the term which it noted has remained unchanged since 1977. See attached 71 Fed Reg 46550 (August 14, 2006). The term “disability” is arguably less pejorative than “disturbance” since “disturbance” has a more “negative” connotation than “disability”. Colloquially, characterizing someone as “disturbed” is generally viewed as derisive or ridiculing.

At least one other state, Virginia, has ostensibly adopted “emotional disability” in its IDEA regulations. See attachment. The Delaware DOE indicates that it views the terms “emotional disturbance” and “emotional disability” as “equivalent”. At 969.

The Councils may wish to either endorse the substitution of terms or comment that there is no objection to the substitution.

10. DMMA Prop. Spousal Impoverishment Undue Hardship Reg. [19 DE Reg. 987 (5/1/16)]

Background on “spousal impoverishment” is summarized in the attached Medicaid.gov overview:

The expense of nursing home care - which ranges from \$5,000 to \$8,000 a month or more - can rapidly deplete the lifetime savings of elderly couples. In 1988, Congress enacted provisions to prevent what has come to be called “spousal impoverishment,” leaving the spouse who is still living at home in the community with little or no income or resources. These provisions help ensure this situation will not occur and that community spouses are able to live out their lives with independence and dignity.

There is a federal minimum resource standard which is updated annually. In 2016, it is \$23,844. States can exceed the federal minimum. Delaware adopted a standard of \$25,000 in 1993. See attachments.

Federal law, 42 U.S.C. 1396r-5(c)(3) (attached) directs states to disregard otherwise countable spousal resources if “the State determines that denial of eligibility would work an undue hardship.” DMMA’s current regulations implement this law:

An institutionalized spouse who (or whose spouse) has excess resources shall not be found ineligible per Section 1924(c)(3) C of the Social Security Act where the state determines that denial of eligibility on the basis of having excess resources would work an undue hardship.

16 DE Admin Code 20950. See also 19 DE Reg. at 989.

DMMA proposes to adopt the following definition of “undue hardship”:

20900.1. Undue Hardship

Spousal Impoverishment rules may be waived if the application of the rules would cause an undue hardship. Undue hardship exists when application of the spousal impoverishment provisions would deprive the individual of medical care such that his/her life would be endangered. Undue hardship also exists when application of the spousal impoverishment provisions would deprive the individual of food, clothing, shelter or other necessities of life.

I have two observations.

First, DMMA should consider an increase in the \$25,000 resource cap adopted in 1993. Consistent with the attachment, \$25,000 in 1993 is equivalent to \$41,199 in 2016. If raised, there would be less need to consider a waiver.

Second, the proposed standard is unduly limiting. Medical expenses can qualify for consideration in the “undue hardship” determination only if the individual would die without the medical care. CMS is more expansive, authorizing an “undue hardship” waiver if the person’s health would be endangered. See, e.g., the attached CMS DRA summary and conforming Pennsylvania policy. Thus, if the loss of medical care would result in excessive pain; loss of a limb; partial paralysis; exacerbation of a diagnosed mental health condition (e.g. depression; schizophrenia); or other deterioration in health, the DMMA workers should be able to consider such effects. Moreover, it would be preferable to modify the third sentence as follows: “Without limitation, undue hardship also exists when application....life.” There should be some recognition that genuine hardship may be presented by factors beyond a short list. For example, a blind individual with an aging seeing-eye dog may need funds for dog food and expensive veterinary care.

The Councils may wish to share the above observations with DMMA with a courtesy copy to AARP.

11. DMMA Proposed ABLE Account Regulation [19 DE Reg. 982 (5/1/16)]

The Division of Medicaid & Medical Assistance proposes to adopt regulations implementing the Achieving a Better Life Experience Act of 2014 (“ABLE” Act). The Act authorizes the establishment of a special account for the benefit of a qualifying individual with a disability. Funds in such an account which will not be a countable resource and distributions from such a fund for a qualified disability expense (“QDE”) are not countable income for public benefits programs. Implementing State legislation was adopted in 2015 and is codified at 16 Del.C. §§9601A- 9608A. New State legislation (H.B. No. 358) was introduced on May 4, 2016. I have not had the opportunity to review the 17-page bill to assess its content.

I have the following observations on the proposed regulation.

First, in §20330.2.1.1, the definition of “person with signature authority” merits reconsideration. The first sentence reads as follows:

“Person with signature authority” means a person who can establish and control an ABLE account for a designated beneficiary who is a minor child or is otherwise incapable of managing an account.

The federal regulations do not require an adult to “be incapable of managing an account” to designate a “person with signature authority. See, e.g., the attached proposed regulation published at 80 Fed Reg. 35611 (June 22, 2015):

If the designated beneficiary is not able to exercise signature authority over his or her ABLE account or chooses to establish an ABLE account but not exercise signature authority, references to the designated beneficiary with respect to his or her actions include actions by the designated beneficiary’s agent under a power of attorney or, if none, a parent or legal guardian of the designated beneficiary.

[emphasis supplied] A “competent” adult can simply choose to not exercise signature authority.

Second, in §20330.2.1.1, the definition of “ABLE program” refers to a program established or maintained “by a State (or agency or instrumentality thereof)....”. This is consistent with the proposed federal regulation. See 80 Fed Reg. at 35612(June 22, 2015). However, I understand that many states are contemplating implementation through a consortium of states. Therefore, DMMA could consider expanding the reference as follows: “by a State or consortium of states (or agency or instrumentality thereof)....”.

Third, for similar reasons, DMMA could consider amending the definition of “eligible individual” as follows: “ a resident of this State, a contracting state, or a state participating in a consortium arrangement who is:...”

Fourth, for similar reasons, DMMA could consider amending §20330.2.1.2.2 as follows: “The State or consortium ABLE program that is administering the account.”

Fifth, in §20330.2.1.1, the definition of “eligible individual” requires the person to be a resident of Delaware or “a contracting state”. The proposed federal regulation would allow some persons (e.g. military) to keep an account even if the person is no longer a resident of the state. See attached 80 Fed Reg at 35608. Therefore, there is some “tension” between the “residency” requirement and the proposed federal regulation. Moreover, consistent with the attached January 11, 2016 article, Congress amended the law so an eligible person can open an account in any state, regardless of where the person resides.

Sixth, in §20330.2.1.3, second sentence, there is a plural pronoun (“their”) with a singular antecedent (“person”). This can be easily corrected by substituting “the person’s” for “their”.

Seventh, in §20330.2.1.5, correct the grammar by substituting “the beneficiary’s” for “their”.

Eighth, §§20330.2.1.6.1 and 20330.2.1.6.2 treat distributions for housing less favorably than other distributions. If a housing distribution is made on May 31 and paid to a landlord on June 1, the entire housing distribution would be considered a countable resource for the month of June. This is an unreasonable approach.

I recommend sharing the above observations with DMMA and policymakers with a courtesy copy to the AARP.

12. H.B. No. 302 (Texting & Hand-held Cell Phone Use While Driving Penalties)

This legislation was introduced on April 6, 2016. As of May 9, it awaited action by the House Public Safety & Homeland Security Committee.

Under current law, a driver using an electronic communication device while a vehicle is in motion is subject to a \$50 civil penalty for a first offense and \$100-\$200 civil penalty for a subsequent offense. No points are assessed. See lines 4-8.. H.B. No. 302 would enhance penalties as follows: \$100 civil penalty for first offense and \$200-\$300 civil penalty for subsequent offense. H.B. No. 302 would also authorize imposition of points for second or subsequent offenses.

An informative history of Delaware’s limits on phone-related distracted driving laws is attached. As it notes, the Delaware House overwhelmingly approved an increase in the civil penalty for a first offense in 2014 to \$75 (H.B. No. 298) but the Senate did not act on the bill. The SCPD endorsed the 2014 legislation. See attached May 29, 2014 letter which noted that Delaware’s penalties were lower than 34 of the 40 states with similar bans.

Updated statistics are compiled in the attachments. The penalty for a first offense in neighboring states is as follows: Maryland - \$500 fine; New Jersey - \$100 fine; and Pennsylvania - \$50 fine. The attached April 12, 2016 News Journal article observes that 18 states add points after a first offense.

Anyone traveling on Delaware roads routinely observes drivers flagrantly violating the law. The \$50 civil penalty is so modest that there is little deterrent effect. Moreover, driving while texting or using a hand-held device greatly increases the risk of accidents and injuries. See attached FCC article noting that driver distraction causes 18% of all fatal crashes and 11% of drivers aged 18-20 who survived a crash admitted they were sending or receiving texts when they crashed. See also attached May 4, 2016 News Journal article, "Simulator shows texting danger".

Given the above considerations, the Councils may wish to consider issuance of a favorable analysis.

13. H.B. No 319 (Substance Exposed Infants)

This legislation was introduced on April 13, 2016. As of May 9, it had been released from the House Judiciary Committee and awaited action by the House. It is earmarked with an incomplete fiscal note.

Similar legislation (H.B. No. 268) was introduced in March, 2016 and stricken on April 14, 2016. The SCPD submitted the attached commentary on that bill. H.B. No. 319 omits some provisions involving "medically fragile children" which were highly disfavored by the Council. However, in some other respects, H.B. 319 replicates some problematic provisions in the prior bill.

Background is included in the attached articles. In a nutshell, approximately 3% of babies born in Delaware qualify for a diagnosis of neonatal abstinence syndrome (NAS) in which the infant undergoes opiate withdrawal. That percentage has been growing in recent years. Indeed, DFS predicts that 600 babies will be born with NAS in Delaware in 2016. See attached April 28, 2016 News Journal article. DFS substantiates abuse in approximately 10% (44/448) of cases of suspected neglect or abuse reported to it among babies born with drugs or alcohol in their system. See attached Mach 7, 2016 News Journal article. Medical professionals prefer to place pregnant women with addictions on methadone resulting in only short-term effects on babies treated for withdrawal upon birth. See attached "Addicted babies", Delaware News Journal (November 20, 2015).

H.B. No. 319 (lines 79-90) would require health care providers to report to DSCY&F infants affected by either: 1) illegal substance abuse by the infant's mother; 2) withdrawal symptoms resulting from prenatal drug exposure (with exceptions); or 3) fetal alcohol spectrum disorder. Although reports of abuse or neglect can generally be made anonymously, this is not permitted for reports of substance exposed infants (lines 108-110). A "plan of safe care" would be developed for cases accepted by DFS for investigation or family assessment (lines 44-60 and 136-137).

I have the following observations.

First, the legislation reinforces an autocratic model in which the State imposes requirements and offers only modest help to new mothers with substance abuse profiles. The bill (lines 44-60) contemplates unilateral development of the “plan of safe care” with zero input from the parent. This “top-down” plan is then shared with agencies but not the parent (lines 48-49 and 56-58). This kafkaesque approach is not a collaborative model which “engages” the new mother in a joint venture to benefit her infant. The “plan of safe care” section should preferably be amended to ensure parental input and collaboration in development of the plan.

Second, the articles describe successful outcomes for parents receiving wrap-around services while highlighting the paucity of resources available to many parents:

Holly Rybinski, of Newport, said she had to go to jail in order to get the drug treatment she needed. That was almost two years ago. She had stayed clean for five years, but while she was pregnant with his child, her partner overdosed and died. Consumed with grief, Rybinski turned to heroin and cocaine during the last five months of her pregnancy. After she gave birth to her son James April 8, 2014, at Christiana Care’s Wilmington Hospital, she was ready to be clean. She said the Division of Family Services told her that they had to take custody of him since James tested positive for drugs, she wasn’t in a treatment program and Rybinski had a record. They told her she had 90 days to find employment, treatment and stable housing and then they could discuss putting him back in her care. That request was easier said than done. ...”I tried five different times to get into treatment,” Rybinski said. “It was one obstacle after the other.” As the number of pregnant and addicted mothers grows, the need for treatment is even more critical. Community members, families and those now in recovery, like Rybinski, have long lamented Delaware’s lack of residential treatment options. Many people have to wait days and even weeks to get a bed. ...Currently, there is one state-run treatment program for expectant or new mothers recovering from addiction in Delaware, but it is only for women who are incarcerated and it is in Newark. ...Brandywine Counseling ran a program for expecting moms wrestling with addiction, called Lighthouse, downstate in Ellendale, but is closed in September due to budget cuts and staffing shortages. ... (I)t was extremely successful. Nearly 100 percent of women were able to give birth to babies free of drugs.

“More treatment key for addicted moms”, Delaware News Journal (March 4, 2016). Given the incomplete fiscal note, it is difficult to assess whether the legislation will expand resources. Obviously, successful outcomes for both mothers and infants are highly dependent on the ready availability of a comprehensive, responsive system of supports.

Third, the “plan of care” section identifies a few types of support services (lines 51-56). It could be improved by adding “safe housing” as a support service. This section also contemplates the identification of family supports (line 50) without including which entity will assure provision of the supports. Merely identifying “available family supports” (lines 50-51) without clarification of the agency responsible for assuring provision of the supports will result in ambiguity and plan failure.

Fourth, the Judiciary Committee Report indicates that the bill was supported since “it provides essential support for families”. In contrast, the text of the bill includes some relatively anemic standards and expectations. For example, lines 123-124 recite that “(t)he system shall endeavor to coordinate community resources...”. There is no definition of “the system” and the reference to “endeavor” (a/ka “try”) establishes a weak expectation. The sentence could be improved by reciting that “(t)he Division shall coordinate community resources...” OR “(t)he Division shall ensure coordination of community resources...”. Likewise, the plan of safe care contemplates simply a “referral” to substance disorder treatment programs and home visiting programs (lines 52 and 54). It would be preferable to include a more affirmative Division role in securing access to such supports than simply issuing a referral.

Fifth, lines 66-69 suggest that a mothers prescribed Methadone (who would still have given birth to infants undergoing withdrawal) are exempt from the operative provisions in the bill. Their babies would not qualify under the definition of “substance exposed infant” (lines 61-63) since they are excluded from the definition of “withdrawal symptoms resulting from prenatal drug exposure” (lines 62 and 66-69). This approach is reinforced by lines 83-89. Reasonable persons might differ on the prudence of this approach since there would be no report to DSCY&F. Moreover, such infants would be categorically ineligible for a “plan of safe care” since such a plan is only available to a “substance exposed infant” (line 45).

The Councils may wish to share conforming commentary with policymakers.

14. H.B. No. 311 (Mental Health Transition Plan)

This legislation was introduced on April 12, 2016. As of May 9, it awaited action by the House Judiciary Committee.

The key authorization in the bill (lines 4-7) is as follows:

When a child 17 years of age or older is in the custody of DSCYF, the Court may order the Department of Health and Social Services to determine whether the child qualifies for adult mental health or behavioral services and, if so, to coordinate with DSCYF to develop and implement a transition plan for mental or behavioral health services for the child.

The plan would include any adult mental health or behavioral health diagnosis, list the prospective adult services for which the child might qualify, and include other information or relief the Court determines relevant to the child’s transition to adulthood. See lines 7-10.

I have the following observations.

First, the transition of minors served by the DSCY&F's Division of Prevention and Behavioral Health Services (DPBHS) to DHSS's Division of Substance Abuse & Mental Health Services (DSAMH) has been a matter of concern for decades. The most significant "tension" between the juvenile and adult systems results from more restrictive eligibility standards in the adult system. For example, the DPBHS serves minors with a wide array of mental health diagnoses while DSAMH has traditionally focused eligibility on persons with severe and persistent mental illness (SPMI). Compare attached DPBHS eligibility standards with DSAMH LTC eligibility standards. DSAMH generally views SPMI to cover certain diagnoses, i.e., schizophrenia, depression, bipolar disorder, and personality disorder. Id. Other DHSS mental health programs (e.g. PROMISE) also have rather prescriptive eligibility standards based on specific diagnoses. See attached excerpt from PROMISE Medicaid waiver standards (August 22, 2014).

Second, the current DPBHS Strategic Plan is published at <http://kids.delaware.gov/pdfs/pbh-StrategicPlanCY13-16-update-2016.01.05.pdf>. The attached excerpt identifies transition from the juvenile to the adult mental health services system as a priority and describes the following initiatives addressing this priority:

- PBH is participating on a youth transition workgroup led by Judge Nicholas in Kent County.
- Project CORE was awarded to PBHS. This is a SAMSHA grant, in concert with DSAMH, to prevent psychosis in youth and young adults and to assist with the transition from youth BH services to the adult BH system.

If not already done, the sponsors of the legislation may wish to assess the status of the "youth transition workgroup" and SAMHSA-funded project addressing transition.

Third, H.B. No. 311 has the following positive features:

A. It would cover transition of youth not only in DPBHS custody, but also in DFS and YRS custody.

B. It provides a mechanism to ensure the collaboration of DSC&F and DHSS in developing a transition plan so transitioning youth do not "fall through the cracks".

C. DHSS has been expanding its mental and behavioral health services support system in recent years. The system has become increasingly complicated and involves a wide array of programs and providers. For example, DMMA-regulated Medicaid MCOs provide mental health and behavioral health services. The federal Court Monitor has been critical of the lack of coordination among the MCOs, DMMA, and DSAMH while noting some recent improvement. See attached excerpt from Eighth Report of the Court Monitor (December 26, 2015). DMMA administers the Community Alternative Disability Program Medicaid program with eligibility up to age 19. See 16 DE Admin Code 25000. The PROMISE program is still in its early stages of implementation. Simply referring a 17 year old (with mental health limitations) to programs will result in a "bewildered" youth who may simply "give up" on trying to navigate the system. Development of a judicially-prompted plan should ensure a smooth transition for such youth.

The Councils may wish to share the above observations with policymakers, including DHSS Administration, DSCY&F Administration, and the Office of the Child Advocate.

15. H.B. No. 310 (Family Court Jurisdiction: Outpatient Treatment)

This legislation was introduced on April 12, 2016. As of May 9, it awaited action by the House Judiciary Committee. It is earmarked with an incomplete fiscal note.

The bill would expand the jurisdiction of the Family Court. A petition could be filed affecting a youth in DSCY&F custody upon turning 18 with a mental illness diagnosis (lines 8-11, 93-100). The petition could be filed when the respondent is between 17 ½ years of age through 20 ½ years of age (lines 10-11) and court jurisdiction could continue until the youth's 26th birthday (lines 12 and 80-81). A wide array of entities could file the petition, i.e., DHSS, DSCY&F, the youth, youth's attorney, or current or former guardian ad litem (lines 17-18). The Court would, at least on an annual basis, conduct a review of the youth's circumstances (lines 50-65). The Court would be authorized to order the youth to participate in services or outpatient treatment (lines 66-69). If the youth fails to comply, the youth could be committed to a mental hospital (lines 78-79). The youth could also ostensibly be jailed under the Court's criminal contempt authority. See line 79 and Title 10 Del.C. §925(3).

I have the following observations.

First, outpatient mental health commitment is an outdated and disfavored approach in the mental health system. Consistent with the attached April 3, 2013 News Journal article, the federal Court Monitor has been highly critical of Delaware's historical "overuse" of outpatient commitment.

Second, the Family Court has previously been authorized to exercise extended jurisdiction when it would facilitate access to services, i.e., the Court can direct agencies to provide support services to dependent and neglected youth up to age 21 [10 Del.C. §929]. This feature is absent from this bill. Indeed, the bill explicitly eschews any support role of the DSCY&F once a youth reaches 18 (lines 90-91). As a result, the bill is purely an autocratic vehicle to promote forced treatment of individuals who happen to have a mental health diagnosis.

Third, recognizing the fundamental liberty interests implicated in analogous civil commitment and guardianship proceedings, the judiciary and Legislature require a host of procedural safeguards. Such safeguards are absent from the bill. Consider the following:

A. There is no right to appointed counsel for the youth in initial proceedings (lines 30-31). It strains credulity to presume that a 17 - 20 year old with mental health limitations will be able to effectively self-represent in covered proceedings. Moreover, initial proceedings are not benign. They involve authorizing Court oversight of every conceivable aspect of the youth's life for an 8-year period (lines 56-65) and the prospect of involuntary orders if the Court disfavors the youth's choices. In later proceedings the Court may offer the youth an attorney rather than appointing counsel (lines 69-71). Query whether a youth with mental health limitations will be able to knowingly and intelligently waive counsel. Contrast 16 Del.C. §5007(3). Cf. Title 12 Del.C. §3901(c) and Chancery Court Rule 176 [Chancery Court automatically appoints counsel for persons subject to involuntary loss of autonomy via guardianship]

B. There is no right to an independent expert witness to contest either the diagnosis or need for involuntary treatment. Contrast 16 Del.C. §5007(3).

C. There is no explicit right to conduct discovery or invoke the right against self- incrimination. Contrast 16 Del.C. §5007(4).

D. The description of initial proceedings omits any reference to the burden of proof or the evidentiary standard . Contrast attached Chancery Court opinion holding that “clear and convincing evidence” standard should apply in civil actions which potentially limit individual rights of self-determination and self-control. At pp. 3-4. The initial proceedings which may culminate in 8-year judicial oversight of a youth’s life should require a higher standard of proof.

E. Court oversight is not limited to mental health. The Court may engage in an unlimited inquiry about the youth’s choices in finances, education, housing, and clothes (lines 58-65).

Fourth, the bill is manifestly unnecessary. There are extensive procedures in place for involuntary mental health commitments and guardianship proceedings. Adding overlapping Family Court proceedings in anticipation of expanding regressive outpatient treatment orders will complicate rather than improve the mental health system.

The Councils may wish to share the above observations with policymakers, including DSCY&F Administration, DHSS Administration, the Office of the Child Advocate, the ACLU, and the federal Court Monitor.

16. H.B. No. 317 (Employment Discrimination: Family Responsibilities)

This legislation was introduced on April 19, 2016. As of May 9, had been released by the House Labor Committee and awaited action by the House.

The bill would add a protected class to Delaware’s employment discrimination law - “family responsibilities”. It would be defined as follows:

(9) “Family responsibilities” means the state of being, or the potential to become, a contributor to the support of a person or persons in a dependent relationship, irrespective of their number, including the state of being the subject of an order of withholding or similar proceedings for the purpose of paying child support or a debt related to child support.

The synopsis indicates that “five states and over 90 localities prohibit discrimination based on family responsibilities to some degree.”

The effect of the bill would ostensibly be broad. Consistent with the attached January 19, 2016 News Journal article, “nearly half of all Delawareans over age 35 provide - or have provided - unpaid long-term care for a loved one who is ill, elderly or lives with a physical or mental disability, according to a survey from AARP.”

There already exists a patchwork of laws which provide some protection against workplace discrimination involving prospective and current caregivers. Pregnant women are protected under both federal and State law [19 Del.C. 711(a)(1)]. Moreover, the ADA prohibits discrimination because of the disability of an individual with whom the worker has a relationship or association, such as a child, spouse or parent. See 42 U.S.C. 12112(b)(4). The EEOC offers the following example: “(A)n employer could not refuse to hire a job applicant whose wife has a disability because the employer assumes that the applicant would have to use frequent leave and arrive late due to his responsibility to care for his wife.” See attached EEOC, “Enforcement Guidance: Unlawful Disparate Treatment of Workers with Caregiving Responsibilities” (2007), Section II. E. It is unclear if Delaware State law covers disability-based discrimination based on a worker’s association with a person with a disability. See 19 Del.C. §§720-728. H.B. No. 317 would cover any State law gap in this context. It would also cover caregivers assisting children without disabilities or the elderly who may not have quite reached the threshold of disability under ADA standards.

The sponsors may wish to consider improving the bill by explicitly adding provisions akin to the “reasonable accommodations” protections for pregnant workers and workers with disabilities. See 19 Del.C. §§710(18), 711(3)a, and 722(6). Reasonable accommodations for a caregiver could include modified work schedules and job restructuring.

The Councils may wish to consider sharing a positive analysis of the bill consistent with the above observations.

17. S.B. No. 230 (Supported Decision-making)

This legislation was introduced on April 14, 2016. It was released from the Senate Health & Social Services Committee on April 20. As of May 9, it awaited action by the Senate.

In recent years, the federal Administration on Aging and the Administration for Intellectual and Developmental Disabilities have promoted the availability of supported decision-making options. Their rationale is that both the elderly and individuals with disabilities may benefit from the availability of assistance which is respectful of their autonomy while offering a menu of supports from which they can choose.

Many national organizations are also promoting the availability of supported decision-making for persons with disabilities. For example, the national ARC and American Association on Intellectual and Developmental Disabilities (AIIDD) adopted the attached position statement in April, 2016, “Autonomy, Decision-Making Supports, and Guardianship”. The national position statement includes the following guidance:

- States should provide systemic access to decision-making supports for all individuals with IDD.
- Each individual...should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime. All persons with I/DD can participate in their own affairs with supports, assistance, and guidance from others, such as family and friends. People with I/DD should be aware of and have access to decision-making supports for their preferred alternatives.

- Less restrictive means of decision-making supports (e.g. health-care proxies, advance directives, supported decision-making, powers of attorney, notarized statements, representation agreements, etc.) should be tried and found to be ineffective in ensuring the individual's decision-making capacity before use of guardianship as an option is considered.

See also attached Joint ARC and AAIID Position Statement, 'Self Determination" (2011).

Representatives of the Department of Health & Social Services, Office of the Public Guardian, Disabilities Law Program, and multiple State Councils formed a workgroup to prepare enabling legislation resulting in S.B. No. 230. The legislation does not supplant guardianship, powers of attorney, or other options available to help individuals with disability-related limitations. Rather, as illustrated in the attached "Comparison of Decision Making Options in Delaware" chart, it is part of a continuum of tools and resources to facilitate decision-making.

In nutshell, the Department of Health & Social Services will publish a form which a "principal" can execute defining the scope of authorized assistance (lines 88-89 and 163). The "supporter" must also sign the form and agree to abide by its terms (lines 98-102). If authorized, the supporter assists the principal in understanding financial, healthcare, and other information (lines 113-114); obtaining information (lines 115-117); making appointments (lines 118-119); and helping organize and keep track of information (lines 120-121).

The bill includes many safeguards:

- A. The DHSS form must be used (lines 88-90).
- B. The form must be signed in the presence of 2 witnesses (line 91).
- C. The supporter and witnesses must not be disqualified based on potential conflicts of interest (lines 92-95 and 124-131).
- D. Supporters are barred from misusing their role or information (lines 132-137).
- E. Supporters must protect the confidentiality of information (lines 159-161).
- F. The principal can revoke the form agreement at any time (lines 105-106).

The supporter essentially assists and facilitates decision-making and implementation of a principal's decisions. The supporter is not a substitute decision-maker (lines 12-13).

Since the legislation enhances the scope of assistance available to individuals, with safeguards, it may merit endorsement.

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STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
MARGARET M. O'NEILL BUILDING
410 FEDERAL STREET, SUITE 1
DOVER, DE 19901

VOICE: (302) 739-3620
TTY/TDD: (302) 739-3699
FAX: (302) 739-6704

MEMORANDUM

DATE: March 29, 2016

TO: Beth Kramer, Criminal History Supervisor
Division of Family Services – Office of Child Care Licensing

FROM: DM-P/ARR
Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

RE: 19 DE Reg. 822 [DFS Child/Health Care Public School & Camp Registry Check Regulation (3/1/16)]

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Services for Children, Youth and Their Families/Division of Family Services (DFS)/Office of Child Care Licensing's proposal to amend its child protection registry standards to conform to enactment of S.B. 144 in the 148th General Assembly with an effective date of April, 2016. The proposed regulation was published as 19 DE Reg. 822 in the March 1, 2016 Register of Regulations. SCPD has the following observations.

First, the regulation appears to omit provisions related to student teachers implementing Title 31 Del.C. §309(e)(1). That statute contemplates submission of registry information to the student teacher's college/university while the regulation only envisions submission of the information to an employer (which does not include a college/university).

Second, §6.4 suggests that the employer is only "requested" to provide a copy of the results to an applicant for employment. The statute envisions DSCYF providing the summary to the individual. See, e.g., Title 31 Del.C. §§309(e)(1)(a) and 309(e)(1)(c). Cf. Title 31 Del.C. §309(e)(2) and (3) [DSCY&F shares determination with individual].

Third, in §3.0, the definition of "person seeking employment" and §4.0 are inconsistent. The former includes volunteers and contractors within the scope of "person seeking employment" while the latter establishes a separate subpart (§4.2) for such persons.

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observations or recommendations on the proposed regulation.

cc: Ms. Victoria Kelly
Ms. Kelly McDowell
Mr. Brian Hartman, Esq.
Governor's Advisory Council for Exceptional Citizens
Developmental Disabilities Council

19reg822dscyf-dfs child-health care public school & camp registry check 3-29-16



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
MARGARET M. O'NEILL BUILDING
410 FEDERAL STREET, SUITE 1
DOVER, DE 19901

VOICE: (302) 739-3620
TTY/TDD: (302) 739-3699
FAX: (302) 739-6704

MEMORANDUM

DATE: March 29, 2016

TO: Beth Kramer, Criminal History Supervisor
Division of Family Services – Office of Child Care Licensing

FROM: DM-P/ARR
Damese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

RE: 19 DE Reg. 821 [DFS Criminal History Record Checks for Child Care Person Regulation (3/1/16)]

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Services for Children, Youth and Their Families/Division of Family Services (DFS)/Office of Child Care Licensing proposal to repeal its current criminal background check standards for persons involved in child care and substitute a new set of standards. The proposed regulation was published as 19 DE Reg. 821 in the March 1, 2016 Register of Regulations. SCPD has the following observations.

In general, the standards are comprehensive and prescriptive. SCPD has only one significant concern. The new regulation applies its standards to an “employee” which is defined as including paid personnel, volunteers, persons with direct access to children, adult household members of child care homes, and applicants to become foster care providers, respite providers, adoptive parents, and their household members. See §2.0, definition of “employee”. While this may be the approach adopted in the statute [Title 31 Del.C. §309(b)(9)], there are several problems with this approach.

First, while the definition of “employee” covers this long list of persons, many regulatory sections refer to employees as distinct from volunteers, foster parents, etc. Compare, e.g., §2.0, definition of “child-serving entity”, §4.6.1.1, §4.7.1, and §5.1.1. If the definition of “employee” covers volunteers, foster parents, etc., it makes no sense to have separate references.

Second, the Administrative Code Style Manual provides the following guidance:

7.2. General Guidelines

In general, keep the language of the text as clear and simple as possible. When drafting, remember that documents should be written so that the general public can understand them. Avoid using language that only individuals with specialized knowledge can understand. Consistency of expression, logical arrangement, and adherence to accepted usage aid readability.

Strive for consistency of terminology, expression, and arrangement. Avoid using the same word or term in more than one sense. Conversely, avoid using different words to denote the same idea. ...

In contrast, the regulation sometimes refers to “employment” as distinct from volunteering or serving as a respite, foster parent, or adoptive parent. Compare §§4.2, 4.4, 4.6.1.1, 4.7.1, 7.1, 7.1.1.1.

Third, encompassing many “non-employees” within the definition of “employee” is counterintuitive and confusing. It’s akin to having a definition of “red” and defining “red” as including blue, green, and yellow. It’s “odd” to characterize volunteers and household members of foster, respite, and adoptive homes as “employees”.

Fourth, the title to the regulation still refers to “child care persons” which was the term used in the prior regulation (§4.1). This term is preferable to “employee” since a variety of persons can be listed under this definition without the term being counterintuitive and confusing.

For the above reasons, the Division may wish to revert to using the current regulatory term, “child care person”, rather than “employee” and otherwise revising the regulation for consistency.

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observations or recommendations on the proposed regulation.

cc: Ms. Victoria Kelly
Ms. Kelly McDowell
Mr. Brian Hartman, Esq.
Governor’s Advisory Council for Exceptional Citizens
Developmental Disabilities Council

19reg821dscyf-dfs criminal history record checks 3-29-16



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
MARGARET M. O'NEILL BUILDING
410 FEDERAL STREET, SUITE 1
DOVER, DE 19901

VOICE: (302) 739-3620
TTY/TDD: (302) 739-3699
FAX: (302) 739-6704

March 29, 2016

Ms. Tina Shockley, Education Associate
Department of Education
401 Federal Street, Suite 2
Dover, DE 19901

RE: 19 DE Reg. 810 [DOE Proposed District & School Emergency Preparedness Policy
Regulation (3/1/16)]

Dear Ms. Shockley:

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Education's (DOE's) proposal to repeal its District and School Emergency Preparedness Policy in its entirety. The proposed regulation was published as 19 DE Reg. 810 in the March 1, 2016 issue of the Register of Regulations. SCPD has the following observations.

The attached Omnibus School Safety Act makes the Department of Safety and Homeland Security (DSHS) primarily responsible for emergency preparedness in public schools. The Act includes the following provision:

(c) The Department ...shall have the overall responsibility for the implementation of the act. In connection therewith, the Department's duties and responsibilities shall include but not be limited to:

...(5) In consultation with the Department of Education, adopting such rules and regulations as shall be necessary or desirable to implement the provisions of the act;...

The Administrative Code reveals no Department of Safety & Homeland Security regulations implementing the law. Literally, regulations are optional under the statute.

The Department is also responsible for submission of a progress report "to the General Assembly by May 31 of each year until such time that implementation of the program is completed and it is fully operational." See Title 29 Del.C. §8237(g).

Repeal of the DOE regulation appears warranted given the statutory responsibility of DSHS under the OSSA. However, SCPD is inquiring about the status of any regulations authorized to

be developed "in consultation with the Department of Education" under Title 29 Del.C. §8237(c)(5). In addition, by way of copy to DSHS, SCPD is soliciting the latest progress report and an update on the status of implementation of the OSSA.

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observations on the proposed regulation.

Sincerely,

Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

cc: The Honorable Steven Godowsky, Ed.D, Secretary of Education
Mr. Chris Kenton, Professional Standards Board
Dr. Teri Quinn Gray, State Board of Education
Ms. Mary Ann Mieczkowski, Department of Education
Ms. Kathleen Geiszler, Esq., Department of Justice
Ms. Terry Hickey, Esq., Department of Justice
Ms. Iona Kirshon, Esq., Department of Justice
Mr. Joe Swiski, DSHS
Mr. Darren Lester, DSHS
Mr. Brian Hartman, Esq.
Developmental Disabilities Council
Governor's Advisory Council for Exceptional Citizens

19reg810 doe-district & school emergency preparedness policy 3-29-16



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
MARGARET M. O'NEILL BUILDING
410 FEDERAL STREET, SUITE 1
DOVER, DE 19901

VOICE: (302) 739-3620
TTY/TDD: (302) 739-3699
FAX: (302) 739-6704

February 22, 2016

Ms. Tina Shockley, Education Associate
Department of Education
401 Federal Street, Suite 2
Dover, DE 19901

RE: 19 DE Reg. 714 [DOE Proposed Parent Councils Regulation]

Dear Ms. Shockley:

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Education's (DOE's) proposal to adopt a regulation related to the establishment and procedures for the creation and maintenance of a parent council for the parents of students with disabilities. The proposed regulation was published as 19 DE Reg. 714 in the February 1, 2016 issue of the Register of Regulations.

The proposed regulation is consistent with the recommendation from the IEP Improvement Task Force created by S.C.R. 63 in the 147th General Assembly which recommended that public schools encourage establishment of parent councils. This recommendation was also incorporated into S.B. 33 which was enacted in June 2015. The legislation contained the following provision:

Each school district and charter school enrolling any child with disabilities shall, on an annual basis, contact parents of each such child to attempt to facilitate the creation and maintenance of a parent council for the parents of students with disabilities. Parent councils will advocate generally for students with disabilities and provide person-to-person support for individual parents and children. The charter schools and school districts shall collaborate and coordinate with existing parent groups and other information and support groups to facilitate creation, maintenance, and effectiveness of the Parent Councils.

SCPD has the following observations.

First, in §25.1, SCPD recommends substituting "child with a disability" for "child with disabilities" to conform to 14 DE Admin Code 922.3.0.

Second, in §25.1, SCPD recommends substituting "in September of each year" for "on an annual basis". This change is still consistent with S.B. 33 but is preferable for multiple reasons.

September is the beginning of the school year when parents are acclimating to new schools. Having a uniform time frame should also facilitate compliance and DOE monitoring.

Third, the DOE regulation "parrots" the statutory language with no embellishment. It would be preferable to include some "prompts" to encourage districts and charter schools to consider various forms of support. They could be encouraged to consider the following: 1) provision of meeting space; 2) posting of agendas and minutes on school/district websites; 3) appointing at least one staff liaison (preferably from special education staff); and 4) offering or facilitating access to training (e.g. from Parent Information Center). This could be achieved by adding the following sentence to §25.3:

Facilitation may include provision of meeting space, appointment of at least one special education staff liaison, posting agendas and minutes on district and charter school websites, and offering or promoting access to training on special education and IEPs.

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observations on the proposed regulation.

Sincerely,



Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

cc: The Honorable Steven Godowsky, Ed.D, Secretary of Education
Mr. Chris Kenton, Professional Standards Board
Dr. Teri Quinn Gray, State Board of Education
Ms. Mary Ann Mieczkowski, Department of Education
Ms. Kathleen Geiszler, Esq., Department of Justice
Ms. Terry Hickey, Esq., Department of Justice
Ms. Ilona Kirshon, Esq., Department of Justice
Mr. Brian Hartman, Esq.
Developmental Disabilities Council
Governor's Advisory Council for Exceptional Citizens

19reg714 doe-parent councils 2-22-16



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
MARGARET M. O'NEILL BUILDING
410 FEDERAL STREET, SUITE 1
DOVER, DE 19901

VOICE: (302) 739-3620
TTY/TDD: (302) 739-3699
FAX: (302) 739-6704

February 22, 2016

Ms. Tina Shockley, Education Associate
Department of Education
401 Federal Street, Suite 2
Dover, DE 19901

RE: 19 DE Reg. 716 [DOE Proposed Charter School Staff Training Regulation]

Dear Ms. Shockley:

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Education's (DOE's) proposal to amend its special education regulations to add a charter school training requirement established by S.B. 33 (codified at 14 Del.C. §3125A). The proposed regulation was published as 19 DE Reg. 716 in the February 1, 2016 issue of the Register of Regulations.

SCPD has only one observation regarding the new §9.0. The legislation (signed 6/18/15) required charter school compliance by January 1, 2016 while the regulation is ostensibly effective on September 1, 2016. Since the regulation is being proposed in February, it cannot become final until Spring. Hopefully, the DOE has alerted charter schools to the need to attend training (scheduled per §9.4.2) rather than deferring such an alert until adoption of the final regulation. The statute was effective on January 1 and does not require adoption of an implementing regulation to be binding on charter schools.

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observation on the proposed regulation.

Sincerely,

Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

cc: The Honorable Steven Godowsky, Ed.D, Secretary of Education
Mr. Chris Kenton, Professional Standards Board
Dr. Teri Quinn Gray, State Board of Education
Ms. Mary Ann Mieczkowski, Department of Education
Ms. Kathleen Geiszler, Esq., Department of Justice
Ms. Terry Hickey, Esq., Department of Justice
Ms. Ilona Kirshon, Esq., Department of Justice
Mr. Brian Hartman, Esq.
Developmental Disabilities Council
Governor's Advisory Council for Exceptional Citizens
19reg716 doe-charter school staff training 2-22-16



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
MARGARET M. O'NEILL BUILDING
410 FEDERAL STREET, SUITE 1
DOVER, DE 19901

VOICE: (302) 739-3620
TTY/TDD: (302) 739-3699
FAX: (302) 739-6704

February 22, 2016

Ms. Tina Shockley, Education Associate
Department of Education
401 Federal Street, Suite 2
Dover, DE 19901

RE: 19 DE Reg. 721 [DOE Proposed Meeting Minutes & Prior Notice Regulation]

Dear Ms. Shockley:

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Education's (DOE's) proposal to amend its regulations regarding IEP meeting minutes and prior written notice for proposed changes. The proposed regulation was published as 19 DE Reg. 721 in the February 1, 2016 issue of the Register of Regulations. SCPD has the following observations.

Meeting Minutes

First, the first sentence of existing §1.5 is revised as follows:

A parent, a parent's authorized representative, or any public agency conducting a meeting, review or conference may take minutes of the meeting, review or conference concerning a child with a disability's free and appropriate public education.

The underlined limitation is problematic since the regulation is "underinclusive". State law contemplates maintenance and access to records not only related to "a free, appropriate, public education" but also "the identification, evaluation and educational program and placement" of a child. See 14 Del.C. §3130(a). For example, if a school conducts a child study team meeting to review results of an initial evaluation of a student, the parents or school may wish to take minutes of the meeting. Since the child is not yet identified, the meeting does not relate to a "FAPE" but does relate to an evaluation to determine eligibility.

The underlined limitation is also inconsistent with 14 DE Admin Code 926.1.3 which is does not

limit the subject of meetings to a “FAPE”:

1.3. Parent participation in meetings. The parents of a child with a disability shall be afforded an opportunity to participate in meetings with respect to the identification, evaluation, and educational placement of the child and the provision of FAPE to the child.

The DOE should either: 1) delete the underlined language; or 2) conform the regulation to encompass both prongs of 14 Del.C. §3130(a). Since §1.3 already describes the subjects of a meeting, it would be preferable to simply delete the underlined language in §1.5.

Second, the DOE proposes to add the following sentence to §1.5:

If initiated by the public agency parents must be offered a digital copy.

This sentence presents two (2) concerns.

A. Since there should be no cost in providing a digital copy, it would be preferable to revise the reference to “...offered a free digital copy”.

B. State law (14 Del.C. §3130) and §1.5 authorize minutes to be taken by stenographer. If a school opts to have a stenographer take minutes, or the school prepares a “paper” copy of the minutes based on an electronic record, the parent could opt to solicit a “paper” copy. The implication of the underlined sentence is that parents would be exclusively limited to a digital copy.

The DOE could consider the following revision:

If initiated by the public agency, parents must be offered, at the parents’ discretion, a [free] digital copy [or, subject to §1.2, a copy in written format].

“Written format” envisions a “paper” copy. See Title 1 Del.C. §302(23).

Prior Notice


First, the revision to §3.2.8 is grammatically infirm and narrower than the applicable statute. Consistent with 14 Del.C. §3134(1), consider the following: “a full, written explanation of all of the procedural safeguards available to parents under state or federal law and regulations.” It is not sufficient to recite that a summary is “available” when the State statute requires the notice to include the explanation of procedural safeguards.

Second, §3.2.6 is “underinclusive” since it is limited to IEP teams. See 14 Del.C. §3134(2). The term “agency” should be substituted for “IEP team”.

Third, the “authority” section at the end of §3.0 should be amended to include 14 Del.C. §§3130, 3133, and 3134.

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observations on the proposed regulation.

Sincerely,



Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

cc: The Honorable Steven Godowsky, Ed.D, Secretary of Education
Mr. Chris Kenton, Professional Standards Board
Dr. Teri Quinn Gray, State Board of Education
Ms. Mary Ann Mieczkowski, Department of Education
Ms. Kathleen Geiszler, Esq., Department of Justice
Ms. Terry Hickey, Esq., Department of Justice
Ms. Ilona Kirshon, Esq., Department of Justice
Mr. Brian Hartman, Esq.
Developmental Disabilities Council
Governor’s Advisory Council for Exceptional Citizens

19reg721 meeting minutes and prior notice 2-22-16



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
MARGARET M. O'NEILL BUILDING
410 FEDERAL STREET, SUITE 1
DOVER, DE 19901

VOICE: (302) 739-3620
TTY/TDD: (302) 739-3699
FAX: (302) 739-6704

February 22, 2016

Ms. Tina Shockley, Education Associate
Department of Education
401 Federal Street, Suite 2
Dover, DE 19901

RE: 19 DE Reg. 718 [DOE Proposed IEP Regulation]

Dear Ms. Shockley:

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Education's (DOE's) proposal to amend its regulations related to IEPs. Some of the changes are prompted by enactment of S.B. 33 in 2015. The proposed regulation was published as 19 DE Reg. 718 in the February 1, 2016 issue of the Register of Regulations. SCPD has the following observations.

First, the grammar in §20.2.2.2 should be corrected since there is a plural pronoun (their) with a singular antecedent (child). This is easily corrected by substituting "the child's" for "their".
Compare §22.3.1.

Second, there is some "tension" between §22.2.3 and 14 Del.C. §3134(1). The statute requires the prior notice to include "a full explanation of procedural safeguards" while the regulation defers the provision of the "full explanation" to the meeting .AND only "offers" a copy of the "full explanation". The regulation should be amended to conform to the statute, i.e., the written "full explanation" should be provided in advance of the IEP meeting with the prior notice.

Third, to improve grammar in §22.3, consider substituting "through the following" for "by".

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observations on the proposed regulation.

Sincerely,


Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

cc: The Honorable Steven Godowsky, Ed.D, Secretary of Education
Mr. Chris Kenton, Professional Standards Board
Dr. Teri Quinn Gray, State Board of Education
Ms. Mary Ann Mieczkowski, Department of Education
Ms. Kathleen Geiszler, Esq., Department of Justice
Ms. Terry Hickey, Esq., Department of Justice
Ms. Ilona Kirshon, Esq., Department of Justice
Mr. Brian Hartman, Esq.
Developmental Disabilities Council
Governor's Advisory Council for Exceptional Citizens

19reg718 IEP 2-22-16

many children with autism are inappropriately placed in alternative educational programs designed for children with serious emotional and behavioral problems.

Discussion: Historically, it has been very difficult for the field to come to consensus on the definition of *emotional disturbance*, which has remained unchanged since 1977. On February 10, 1993, the Department published a "Notice of Inquiry" in the *Federal Register* (58 FR 7938) soliciting comments on the existing definition of *serious emotional disturbance*. The comments received in response to the notice of inquiry expressed a wide range of opinions and no consensus on the definition was reached. Given the lack of consensus and the fact that Congress did not make any changes that required changing the definition, the Department recommended that the definition of *emotional disturbance* remain unchanged. We reviewed the Act and the comments received in response to the NPRM and have come to the same conclusion. Therefore, we decline to make any changes to the definition of *emotional disturbance*.

Changes: None.

Comment: One commenter suggested that the regulations include a process to identify children who are at risk for having an emotional disturbance.

Discussion: We decline to include a process to identify children who are at risk for having an emotional disturbance. A child who is at risk for having any disability under the Act is not considered a *child with a disability* under § 300.8 and section 602(3) of the Act and, therefore, is not eligible for services under the Act.

Changes: None.

Mental Retardation (§ 300.8(c)(6))

Comment: One commenter suggested using the term "intellectual disability" in place of "mental retardation" because "intellectual disability" is a more acceptable term. The commenter also stated that the definition of *mental retardation* is outdated, and should, instead, address a child's functional limitations in specific life areas.

Discussion: Section 602(3)(A) of the Act refers to a "child with mental retardation," not a "child with intellectual disabilities," and we do not see a compelling reason to change the term. However, States are free to use a different term to refer to a child with mental retardation, as long as all children who would be eligible for special education and related services under the Federal definition of *mental retardation* receive FAPE.

We do not believe the definition of *mental retardation* needs to be changed because it is defined broadly enough in § 300.8(c)(6) to include a child's functional limitations in specific life areas, as requested by the commenter. There is nothing in the Act or these regulations that would prevent a State from including "functional limitations in specific life areas" in a State's definition of *mental retardation*, as long as the State's definition is consistent with these regulations.

Changes: None.

Multiple Disabilities (§ 300.8(c)(7))

Comment: One commenter asked why the category of multiple disabilities is included in the regulations when it is not in the Act.

Discussion: The definition of *multiple disabilities* has been in the regulations since 1977 and does not expand eligibility beyond what is provided for in the Act. The definition helps ensure that children with more than one disability are not counted more than once for the annual report of children served because States do not have to decide among two or more disability categories in which to count a child with multiple disabilities.

Changes: None.

Orthopedic Impairment (§ 300.8(c)(8))

Comment: One commenter requested that the examples of congenital anomalies in the definition of *orthopedic impairment* in current § 300.7(c)(8) be retained.

Discussion: The examples of congenital anomalies in current § 300.7(c)(8) are outdated and unnecessary to understand the meaning of *orthopedic impairment*. We, therefore, decline to include the examples in § 300.8(c)(8).

Changes: None.

Other Health Impairment (§ 300.8(c)(9))

Comment: We received a significant number of comments requesting that we include other examples of specific acute or chronic health conditions in the definition of *other health impairment*. A few commenters recommended including children with dysphagia because these children have a swallowing and feeding disorder that affects a child's vitality and alertness due to limitations in nutritional intake. Other commenters recommended including FAS, bipolar disorders, and organic neurological disorders. Numerous commenters requested including Tourette syndrome disorders in the definition of *other health impairment* because children with Tourette syndrome are frequently

misclassified as emotionally disturbed. A number of commenters stated that Tourette syndrome is a neurological disorder and not an emotional disorder, yet children with Tourette syndrome continue to be viewed as having a behavioral or conduct disorder and, therefore, do not receive appropriate special education and related services.

Discussion: The list of acute or chronic health conditions in the definition of *other health impairment* is not exhaustive, but rather provides examples of problems that children have that could make them eligible for special education and related services under the category of other health impairment. We decline to include dysphagia, FAS, bipolar disorders, and other organic neurological disorders in the definition of *other health impairment* because these conditions are commonly understood to be health impairments. However, we do believe that Tourette syndrome is commonly misunderstood to be a behavioral or emotional condition, rather than a neurological condition. Therefore, including Tourette syndrome in the definition of *other health impairment* may help correct the misperception of Tourette syndrome as a behavioral or conduct disorder and prevent the misdiagnosis of their needs.

Changes: We have added Tourette syndrome as an example of an acute or chronic health problem in § 300.8(c)(9)(i).

Comment: A few commenters expressed concern about determining a child's eligibility for special education services under the category of other health impairment based on conditions that are not medically determined health problems, such as "central auditory processing disorders" or "sensory integration disorders." One commenter recommended that the regulations clarify that "chronic or acute health problems" refer to health problems that are universally recognized by the medical profession.

Discussion: We cannot make the change requested by the commenters. The determination of whether a child is eligible to receive special education and related services is made by a team of qualified professionals and the parent of the child, consistent with § 300.306(a)(1) and section 614(b)(4) of the Act. The team of qualified professionals and the parent of the child must base their decision on careful consideration of information from a variety of sources, consistent with § 300.306(c). There is nothing in the Act that requires the team of qualified professionals and the parent to consider only health problems that are

Virginia Department of Education

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SPECIFIC DISABILITIES

EMOTIONAL DISABILITY

It is common for the terms emotional disturbance or disability and behavioral disorder to be used interchangeably. The federal and state regulations define emotional disability as:

...a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree, which adversely affects educational performance:

- An inability to learn which cannot be explained by intellectual, sensory, or health factors;
- An inability to build or maintain satisfactory interpersonal relationships with peers and teachers;
- Inappropriate types of behavior or feelings under normal circumstances;
- A general pervasive mood of unhappiness or depression; or
- A tendency to develop physical symptoms or fears associated with personal or school problems.

The term includes children who are schizophrenic, but does not include children who are socially maladjusted unless it is determined that they are emotionally disturbed.

In considering students as having an emotional disability the multidisciplinary team must answer if the behaviors have existed over a long period of time, not just on occasion or for a short period of time; and to a serious degree, that interferes with their learning. Identification of students with emotional disability may, like other disabilities span a range from mild to moderate or severe.

Professionals agree that working with students identified with an emotional disability requires systematic educational programming and support.

Resources

Better Serving Students with Emotional Disabilities: A Virginia Plan, August 23, 2010


- Emotional Disabilities Summit Information
 - [Summit Proceedings](#) (PDF)
 - [Evidence-based Practices and References](#) (PDF)
 - [Presentation - Robert Gable and Stephen Tonelson](#) (PDF)
 - [Presentation - Richard Van Acker](#) (PDF)
- [Functional Behavioral Assessment \(FBA\) Guidelines](#) (PDF)
 - Appendix A Forms:
 - [Functional Assessment Checklist for Teachers and Staff \(FACTS-Part A\)](#) (PDF)
 - [Functional Behavioral Assessment Interview Forms](#) (PDF)
 - [ABC Observation Form and Functional Assessment Scatterplot](#) (PDF)
 - [Problem Behavior Questionnaire](#) (PDF)
- [Guidelines for the Development of Policies and Procedures for Managing Student Behaviors In Emergency Situations in Virginia Public Schools](#) (PDF)

- [Guidance Document on Manifestation Determination \(PDF\)](#)
 - [Training & Technical Assistance Centers \(TTAC\)](#)
-

Outside Resources

- Federal Agencies
 - [The U.S. Department of Education's Office of Special Education Programs](#)
 - [A Guide to the Individualized Education Program \(USED\)](#)
 - [Special Education and Rehabilitative Services \(OSERS\)](#)
 - [Office for Civil Rights](#)
- State Agencies
 - [Virginia Department of Behavioral Health and Developmental Services](#)
- [Old Dominion University Effective Schoolwide Discipline](#)
- [TTAC Online](#) – A community linking people and resources to help children and youth with disabilities.

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Spousal Impoverishment

The expense of nursing home care — which ranges from \$5,000 to \$8,000 a month or more — can rapidly deplete the lifetime savings of elderly couples. In 1988, Congress enacted provisions to prevent what has come to be called "spousal impoverishment," leaving the spouse who is still living at home in the community with little or no income or resources. These provisions help ensure that this situation will not occur and that community spouses are able to live out their lives with independence and dignity.

Under the Medicaid spousal impoverishment provisions, a certain amount of the couple's combined resources is protected for the spouse living in the community. Depending on how much of his or her own income the community spouse actually has, a certain amount of income belonging to the spouse in the institution can also be set aside for the community spouse's use.

Following is the minimum and maximum amount of resources and income that can be protected for a spouse in the community in 2016:

- [2016 Spousal Impoverishment Standard \(/medicaid-chip-program-information/by-topics/eligibility/downloads/2016-ssi-and-spousal-impoverishment-standards.pdf\)](#)

Post-Eligibility Treatment of Income

The post eligibility calculation is made to determine how much an individual in an institution (usually a nursing home) is able to contribute to cost of his/her own care. It applies only to individuals who are institutionalized (most commonly to those in nursing facilities) and to certain individuals receiving home and community-based waiver services. The process only applies to those with income and only after their Medicaid eligibility has been established.

The contribution is determined by first calculating the individual's total income and then deducting certain amounts from that income. Specifically, the individual's contribution is his or her total income less the following deductions (often referred to as "protected amounts"):

- A personal needs allowance of at least \$30;
- If there is a community spouse and the spousal impoverishment rules discussed above apply, a community spouse's monthly income allowance (at least \$1,939 but not exceeding \$2,931 for 2014), as long as the income is actually made available to the community spouse;
- A family monthly income allowance, if there are other family members living in the household;
- An amount for medical expenses incurred by the spouse who is in the medical facility.

Once the above items are deducted from the institutionalized individual's income, any remaining income is contributed toward the cost of his or her care in the institution.

Eligibility Content

- [Populations \(/medicaid-chip-program-information/by-population/by-population.html\)](#)
- [Spousal Impoverishment \(/medicaid-chip-program-information/by-topics/eligibility/spousal-impoverishment-page.html\)](#)
- [Estate Recovery \(/medicaid-chip-program-information/by-topics/eligibility/estate-recovery.html\)](#)
- [TPL/COB \(/medicaid-chip-program-information/by-topics/eligibility/tpl-cob-page.html\)](#)

Related Resources

- [SMD: Affordable Care Act's Amendments to the Spousal Impoverishment Statute \(/federal-policy-guidance/downloads/smd050715.pdf\)](#)
- [42 CFR 435.725 - Post-eligibility treatment of income of institutionalized individuals in SSI States \(http://www.gpo.gov/fdsys/pkg/CFR-2010-title42-vol4/pdf/CFR-2010-title42-vol4-sec435-725.pdf\)](#)
- [42 CFR 435.733 - Post-eligibility treatment of income of institutionalized individuals in States using more restrictive requirements than SSI \(http://www.gpo.gov/fdsys/search/pagedetails.action?na=&se=&sm=&fl=&ercode=&dateBrowse=&collection=&historical=false&st=42+CFR+435.733&=42+CFR+435.725&psh=&sbh=&tfh=&originalSearch=&sb=re/2010-title42-vol4-sec435-733&packageId=CFR-2010-title42-vol4\)](#)
- [435.735 Post-eligibility treatment of income and resources of individuals receiving home and community-based services furnished under a waiver \(http://www.gpo.gov/fdsys/pkg/CFR-2010-title42-vol4/pdf/CFR-2010-title42-vol4-sec435-735.pdf\)](#)
- [435.832 Post-eligibility treatment of income of institutionalized individuals \(http://www.gpo.gov/fdsys/pkg/CFR-2010-title42-vol4/pdf/CFR-2010-title42-vol4-sec435-832.pdf\)](#)

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CHAPTER 88
FORMERLY
SENATE BILL NO. 99

AN ACT AUTHORIZING AND DIRECTING THE DEPARTMENT OF HEALTH AND SOCIAL SERVICES OF THE STATE OF DELAWARE TO AMEND THE SPOUSAL IMPOVERISHMENT PROVISIONS OF THE STATE PLAN UNDER TITLE XIX (MEDICAID) OF THE SOCIAL SECURITY ACT.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF DELAWARE:

Section 1. The Department of Health and Social Services of the State of Delaware is hereby authorized and directed to amend the spousal impoverishment provisions of the State Plan under Title XIX (Medicaid) of the Social Security Act to reflect the following minimum resources eligibility limitation:

"Minimum Resource Standard: \$25,000".

Approved July 6, 1993.



STATE OF DELAWARE
DELAWARE HEALTH AND SOCIAL SERVICES
DIVISION OF MEDICAID & MEDICAL ASSISTANCE
POLICY, PLANNING AND QUALITY UNIT

MEMORANDUM

REPLY TO
ATTN. OF: Administrative Notice DMMA -03-2016

TO: All DMMA Staff

DATE: November 20, 2015

SUBJECT: 2016 Spousal Impoverishment Standards

BACKGROUND

Under Section 1924(g) of the Social Security Act, the minimum and maximum resource allowances and the cap on the community spouse's minimum monthly maintenance needs standards are updated annually. The figures are increased by the same percentage as the percentage increase in the Consumer Price Index (CPI).

DISCUSSION

The CPI will not increase in 2016. Therefore, the Spousal Impoverishment Standards will remain the same for 2016.

Effective January 1, 2016 the standards will remain as follows:

Minimum Community Spouse Resource Allowance - \$23,844.00 (federal)

Delaware's Minimum Community Spouse Resource Allowance - \$25,000.00

NOTE: Effective October 1, 1993 the minimum resource allowance in Delaware increased to \$25,000.00. Any federal annual increase in the minimum resource allowance will have no effect on Delaware's minimum until it exceeds \$25,000.00

Maximum Community Spouse Resource Allowance - \$119,220.00

Maximum Monthly Maintenance Needs Allowance - \$2,980.50

ACTION REQUIRED

The eligibility system will retain these standards for 2016.

DIRECT INQUIRIES TO

Kathleen J. Mahoney
(302) 424-7214

November 20, 2015
DATE

Glyne Williams
Glyne Williams, Chief
Policy, Planning and Quality
Division of Medicaid & Medical Assistance

2016

SSI and Spousal Impoverishment Standards

Supplemental Security Income (SSI)

Effective 1-1-16

	SSI Federal Benefit Benefit Rate (FBR)	SSI Resource Standard	Income Cap Limit (300%)	Earned Income Break Even Point	Unearned Income Break Even Point
Individual	733.00	2,000.00	2,199.00	1,551.00	753.00
Couple	1,100.00	3,000.00	N/A	2,285.00	1,120.00

Substantial Gainful Activity (SGA) Limit: 1,130.00 (Blind SGA: 1,820.00)

CPI Increase for 2016: 0%

CPI Increase, Since September 1988: 98.6%

Spousal Impoverishment

Effective 1-1-16 Unless Otherwise Noted

Minimum Monthly Maintenance Needs Allowance (MMMNA):
(Effective 7-1-15)

1,991.25	All States (Except Alaska and Hawaii)
2,490.00	Alaska
2,291.25	Hawaii

Maximum Monthly Maintenance Needs Allowance:

2,980.50

Community Spouse Monthly Housing Allowance:
(Effective 7-1-15)

597.38	All States (Except Alaska and Hawaii)
747.00	Alaska
687.38	Hawaii

Community Spouse Resources:

Minimum Resource Standard:
Maximum Resource Standard

23,844.00
119,220.00

Home Equity Limits:

Minimum:
Maximum:

552,000.00
828,000.00



TREATMENT OF INCOME AND RESOURCES FOR CERTAIN INSTITUTIONALIZED SPOUSES

SEC. 1924. [42 U.S.C. 1396r-5] (a) SPECIAL TREATMENT FOR INSTITUTIONALIZED SPOUSES.—

(1) SUPERSEDES OTHER PROVISIONS.—In determining the eligibility for medical assistance of an institutionalized spouse (as defined in subsection (h)(1)), the provisions of this section supersede any other provision of this title (including sections 1902(a)(17) and 1902(f)) which is inconsistent with them.

(2) NO COMPARABLE TREATMENT REQUIRED.—Any different treatment provided under this section for institutionalized spouses shall not, by reason of paragraph (10) or (17) of section 1902(a), require such treatment for other individuals.

(3) DOES NOT AFFECT CERTAIN DETERMINATIONS.—Except as this section specifically provides, this section does not apply to—

(A) the determination of what constitutes income or resources, or

(B) the methodology and standards for determining and evaluating income and resources.

(4) APPLICATION IN CERTAIN STATES AND TERRITORIES.—

(A) APPLICATION IN STATES OPERATING UNDER DEMONSTRATION PROJECTS.—In the case of any State which is providing medical assistance to its residents under a waiver granted under section 1115, the Secretary shall require the State to meet the requirements of this section in the same manner as the State would be required to meet such requirement if the State had in effect a plan approved under this title.

(B) NO APPLICATION IN COMMONWEALTHS AND TERRITORIES.—This section shall only apply to a State that is one of the 50 States or the District of Columbia.

(5) APPLICATION TO INDIVIDUALS RECEIVING SERVICES UNDER PACE PROGRAMS.

—This section applies to individuals receiving institutional or noninstitutional services under a PACE demonstration waiver program (as defined in section 1934(a)(7)) or under a PACE program under section 1934 or 1894.

(b) RULES FOR TREATMENT OF INCOME.—

(1) SEPARATE TREATMENT OF INCOME.—During any month in which an institutionalized spouse is in the institution, except as provided in paragraph (2), no income of the community spouse shall be deemed available to the institutionalized spouse.

(2) ATTRIBUTION OF INCOME.—In determining the income of an institutionalized spouse or community spouse for purposes of the post-eligibility income determination described in subsection (d), except as otherwise provided in this section and regardless of any State laws relating to community property or the division of marital property, the following rules apply:

(A) NON-TRUST PROPERTY.—Subject to subparagraphs (C) and (D), in the case of income not from a trust, unless the instrument providing the income otherwise specifically provides—

(i) if payment of income is made solely in the name of the institutionalized spouse or the community spouse, the income shall be considered available only to that respective spouse;

(ii) if payment of income is made in the names of the institutionalized spouse and the community spouse, one-half of the income shall be considered available to each of them; and

(iii) if payment of income is made in the names of the institutionalized spouse or the community spouse, or both, and to another person or persons, the income shall be considered available to each spouse in proportion to the spouse's interest (or, if payment is made with respect to both spouses and no such interest is specified, one-half of the joint interest shall be considered available to each spouse).

(B) TRUST PROPERTY.—In the case of a trust—

(i) except as provided in clause (ii), income shall be attributed in accordance with the provisions of this title (including sections 1902(a)(17) and 1917(d)), and

(ii) income shall be considered available to each spouse as provided in the trust, or, in the absence of a specific provision in the trust—

(I) if payment of income is made solely to the institutionalized spouse or the community spouse, the income shall be considered available only to that respective spouse;

(II) if payment of income is made to both the institutionalized spouse and the community spouse, one-half of the income shall be considered available to each of them; and

(III) if payment of income is made to the institutionalized spouse or the community spouse, or both, and to another person or persons, the income shall be considered available to each spouse in proportion to the spouse's interest (or, if payment is made with respect to both spouses and no such interest is specified, one-half of the joint interest shall be considered available to each spouse).

(C) PROPERTY WITH NO INSTRUMENT.—In the case of income not from a trust in which there is no instrument establishing ownership, subject to subparagraph (D), one-half of the income shall be considered to be available to the institutionalized spouse and one-half to the community spouse.

(D) REBUTTING OWNERSHIP.—The rules of subparagraphs (A) and (C) are superseded to the extent that an institutionalized spouse can establish, by a preponderance of the evidence, that the ownership interests in income are other than as provided under such subparagraphs.

(c) RULES FOR TREATMENT OF RESOURCES.—

(1) COMPUTATION OF SPOUSAL SHARE AT TIME OF INSTITUTIONALIZATION.—

(A) TOTAL JOINT RESOURCES.—There shall be computed (as of the beginning of the first continuous period of institutionalization (beginning on or after September 30, 1989) of the institutionalized spouse)—

(i) the total value of the resources to the extent either the institutionalized spouse or the community spouse has an ownership interest, and

(ii) a spousal share which is equal to 1/2 of such total value.

(B) ASSESSMENT.—At the request of an institutionalized spouse or community spouse, at the beginning of the first continuous period of institutionalization (beginning on or after September 30, 1989) of the institutionalized spouse and upon the receipt of relevant documentation of resources, the State shall promptly assess and document the total value described in subparagraph (A)(i) and shall provide a copy of such assessment and documentation to each spouse and shall retain a copy of the assessment for use under this section. If the request is not part of an application for medical assistance under this title, the State may, at its

option as a condition of providing the assessment, require payment of a fee not exceeding the reasonable expenses of providing and documenting the assessment. At the time of providing the copy of the assessment, the State shall include a notice indicating that the spouse will have a right to a fair hearing under subsection (e)(2).

(2) **ATTRIBUTION OF RESOURCES AT TIME OF INITIAL ELIGIBILITY DETERMINATION.**—In determining the resources of an institutionalized spouse at the time of application for benefits under this title, regardless of any State laws relating to community property or the division of marital property—

(A) except as provided in subparagraph (B), all the resources held by either the institutionalized spouse, community spouse, or both, shall be considered to be available to the institutionalized spouse, and

(B) resources shall be considered to be available to an institutionalized spouse, but only to the extent that the amount of such resources exceeds the amount computed under subsection (f)(2)(A) (as of the time of application for benefits).

(3) **ASSIGNMENT OF SUPPORT RIGHTS.**—The institutionalized spouse shall not be ineligible by reason of resources determined under paragraph (2) to be available for the cost of care where—

(A) the institutionalized spouse has assigned to the State any rights to support from the community spouse;

(B) the institutionalized spouse lacks the ability to execute an assignment due to physical or mental impairment but the State has the right to bring a support proceeding against a community spouse without such assignment; or

(C) the State determines that denial of eligibility would work an undue hardship.

(4) **SEPARATE TREATMENT OF RESOURCES AFTER ELIGIBILITY FOR BENEFITS ESTABLISHED.**—During the continuous period in which an institutionalized spouse is in an institution and after the month in which an institutionalized spouse is determined to be eligible for benefits under this title, no resources of the community spouse shall be deemed available to the institutionalized spouse.

(5) **RESOURCES DEFINED.**—In this section, the term “resources” does not include—

(A) resources excluded under subsection (a) or (d) of section 1613, and

(B) resources that would be excluded under section 1613(a)(2)(A) but for the limitation on total value described in such section.

(d) **PROTECTING INCOME FOR COMMUNITY SPOUSE.**—

(1) **ALLOWANCES TO BE OFFSET FROM INCOME OF INSTITUTIONALIZED SPOUSE.**—After an institutionalized spouse is determined or redetermined to be eligible for medical assistance, in determining the amount of the spouse’s income that is to be applied monthly to payment for the costs of care in the institution, there shall be deducted from the spouse’s monthly income the following amounts in the following order:

(A) A personal needs allowance (described in section 1902(q)(1)), in an amount not less than the amount specified in section 1902(q)(2).

(B) A community spouse monthly income allowance (as defined in paragraph (2)), but only to the extent income of the institutionalized spouse is made available to (or for the benefit of) the community spouse.

(C) A family allowance, for each family member, equal to at least 1/3 of the amount by which the amount described in paragraph (3)(A)(i) exceeds the amount of the monthly income of that family member.

(D) Amounts for incurred expenses for medical or remedial care for the institutionalized spouse (as provided under section 1902(r)).

In subparagraph (C), the term "family member" only includes minor or dependent children, dependent parents, or dependent siblings of the institutionalized or community spouse who are residing with the community spouse.

(2) COMMUNITY SPOUSE MONTHLY INCOME ALLOWANCE DEFINED.—In this section (except as provided in paragraph (5)), the "community spouse monthly income allowance" for a community spouse is an amount by which—

(A) except as provided in subsection (e), the minimum monthly maintenance needs allowance (established under and in accordance with paragraph (3)) for the spouse, exceeds

(B) the amount of monthly income otherwise available to the community spouse (determined without regard to such an allowance).

(3) ESTABLISHMENT OF MINIMUM MONTHLY MAINTENANCE NEEDS ALLOWANCE.—

(A) IN GENERAL.—Each State shall establish a minimum monthly maintenance needs allowance for each community spouse which, subject to subparagraph (C), is equal to or exceeds—

(i) the applicable percent (described in subparagraph (B)) of 1/12 of the income official poverty line (defined by the Office of Management and Budget and revised annually in accordance with section 673(2) of the Omnibus Budget Reconciliation Act of 1981⁽¹⁸⁸⁾) for a family unit of 2 members; plus

(ii) an excess shelter allowance (as defined in paragraph (4)).

A revision of the official poverty line referred to in clause (i) shall apply to medical assistance furnished during and after the second calendar quarter that begins after the date of publication of the revision.

(B) APPLICABLE PERCENT.—For purposes of subparagraph (A)(i), the "applicable percent" described in this paragraph, effective as of—

(i) September 30, 1989, is 122 percent,

(ii) July 1, 1991, is 133 percent, and

(iii) July 1, 1992, is 150 percent.

(C) CAP ON MINIMUM MONTHLY MAINTENANCE NEEDS ALLOWANCE.—The minimum monthly maintenance needs allowance established under subparagraph (A) may not exceed \$1,500 (subject to adjustment under subsections (e) and (g)).

(4) EXCESS SHELTER ALLOWANCE DEFINED.—In paragraph (3)(A)(ii), the term "excess shelter allowance" means, for a community spouse, the amount by which the sum of—

(A) the spouse's expenses for rent or mortgage payment (including principal and interest), taxes and insurance and, in the case of a condominium or cooperative, required maintenance charge, for the community spouse's principal residence, and

(B) the standard utility allowance (used by the State under section 5(e) of the Food and Nutrition Act of 2008⁽¹⁸⁹⁾) or, if the State does not use such an allowance, the spouse's actual utility expenses,

exceeds 30 percent of the amount described in paragraph (3)(A)(i), except that, in the case of a condominium or cooperative, for which a maintenance charge is included under subparagraph (A), any allowance under subparagraph (B) shall be reduced to the extent the maintenance charge includes utility expenses.

(5) COURT ORDERED SUPPORT.—If a court has entered an order against an institutionalized spouse for monthly income for the support of the community spouse, the community spouse monthly income allowance for the spouse shall be not less than the amount of the monthly income so ordered.

(6) APPLICATION OF "INCOME FIRST" RULE TO REVISION OF COMMUNITY SPOUSE RESOURCE ALLOWANCE.—For purposes of this subsection and subsections (c) and (e), a State must consider that all income of the institutionalized spouse that could be made available to a community spouse, in accordance with the calculation of the community spouse monthly income allowance under this subsection, has been made available before the State allocates to the community spouse an amount of resources adequate to provide the difference between the minimum monthly maintenance needs allowance and all income available to the community spouse.

(e) NOTICE AND FAIR HEARING.—

(1) NOTICE.—Upon—

(A) a determination of eligibility for medical assistance of an institutionalized spouse, or

(B) a request by either the institutionalized spouse, or the community spouse, or a representative acting on behalf of either spouse,

each State shall notify both spouses (in the case described in subparagraph (A)) or the spouse making the request (in the case described in subparagraph (B)) of the amount of the community spouse monthly income allowance (described in subsection (d)(1)(B)), of the amount of any family allowances (described in subsection (d)(1)(C)), of the method for computing the amount of the community spouse resources allowance permitted under subsection (f), and of the spouse's right to a fair hearing under this subsection respecting ownership or availability of income or resources, and the determination of the community spouse monthly income or resource allowance.

(2) FAIR HEARING.—

(A) IN GENERAL.—If either the institutionalized spouse or the community spouse is dissatisfied with a determination of—

(i) the community spouse monthly income allowance;

(ii) the amount of monthly income otherwise available to the community spouse (as applied under subsection (d)(2)(B));

(iii) the computation of the spousal share of resources under subsection (c)(1);

(iv) the attribution of resources under subsection (c)(2); or

(v) the determination of the community spouse resource allowance (as defined in subsection (f)(2));

such spouse is entitled to a fair hearing described in section 1902(a)(3) with respect to such determination if an application for benefits under this title has been made on behalf of the institutionalized spouse. Any such hearing respecting the determination of the community spouse resource allowance shall be held within 30 days of the date of the request for the hearing.

(B) REVISION OF MINIMUM MONTHLY MAINTENANCE NEEDS ALLOWANCE.—If either such spouse establishes that the community spouse needs income, above the level otherwise provided by the minimum monthly maintenance needs allowance, due to exceptional circumstances resulting in significant financial duress, there shall be substituted, for the minimum monthly maintenance needs allowance in subsection (d)(2)(A), an amount adequate to provide such additional income as is necessary.

(C) REVISION OF COMMUNITY SPOUSE RESOURCE ALLOWANCE.—If either such spouse establishes that the community spouse resource allowance (in relation to the amount of income generated by such an allowance) is inadequate to raise the community spouse's income to the minimum monthly maintenance needs allowance, there shall be substituted, for the community spouse resource

allowance under subsection (f)(2), an amount adequate to provide such a minimum monthly maintenance needs allowance.

(f) PERMITTING TRANSFER OF RESOURCES TO COMMUNITY SPOUSE.—

(1) IN GENERAL.—An institutionalized spouse may, without regard to section 1917(c)(1), transfer an amount equal to the community spouse resource allowance (as defined in paragraph (2)), but only to the extent the resources of the institutionalized spouse are transferred to (or for the sole benefit of) the community spouse. The transfer under the preceding sentence shall be made as soon as practicable after the date of the initial determination of eligibility, taking into account such time as may be necessary to obtain a court order under paragraph (3).

(2) COMMUNITY SPOUSE RESOURCE ALLOWANCE DEFINED.—In paragraph (1), the “community spouse resource allowance” for a community spouse is an amount (if any) by which—

(A) the greatest of—

(i) \$12,000 (subject to adjustment under subsection (g)), or, if greater (but not to exceed the amount specified in clause (ii)(II)) an amount specified under the State plan,

(ii) the lesser of (I) the spousal share computed under subsection (c)(1), or (II) \$60,000 (subject to adjustment under subsection (g)),

(iii) the amount established under subsection (e)(2); or

(iv) the amount transferred under a court order under paragraph (3);

exceeds

(B) the amount of the resources otherwise available to the community spouse (determined without regard to such an allowance).

(3) TRANSFERS UNDER COURT ORDERS.—If a court has entered an order against an institutionalized spouse for the support of the community spouse, section 1917 shall not apply to amounts of resources transferred pursuant to such order for the support of the spouse or a family member (as defined in subsection (d)(1)).

(g) INDEXING DOLLAR AMOUNTS.—For services furnished during a calendar year after 1989, the dollar amounts specified in subsections (d)(3)(C), (f)(2)(A)(i), and (f)(2)(A)(ii)(II) shall be increased by the same percentage as the percentage increase in the consumer price index for all urban consumers (all items; U.S. city average) between September 1988 and the September before the calendar year involved.

(h) DEFINITIONS.—In this section:

(1) The term “institutionalized spouse” means an individual who—

(A) [190] is in a medical institution or nursing facility or who (at the option of the State) is described in section 1902(a)(10)(A)(ii)(VI), and

(B) is married to a spouse who is not in a medical institution or nursing facility; but does not include any such individual who is not likely to meet the requirements of subparagraph (A) for at least 30 consecutive days.

(2) The term “community spouse” means the spouse of an institutionalized spouse.

[188] See Vol. II, P.L. 97-35, §673(2).

[189] See Vol. II, P.L. 88-525, §5(e).

[190] See Vol. II, P.L. 111-148, §2404, with respect to protection for recipients of home and community-based services against spousal impoverishment.

(<http://www.usinflationcalculator.com/>)

The US Inflation Calculator measures the buying power of the dollar over time. Just enter any two dates between 1913 and 2016, an amount, and click 'Calculate'.

Inflation Calculator

If in (enter year)

I purchased an item for \$

then in (enter year)

that same **item would cost:** \$41,199.31

Cumulative rate of inflation: 64.8%

*Learn how this calculator works (<http://www.usinflationcalculator.com/frequently-asked-questions-faqs/#HowInflationCalculatorWorks>). This US Inflation Calculator uses the latest US government CPI data (<http://www.usinflationcalculator.com/inflation-calculator-information/consumer-price-index-and-annual-percent-changes-from-1913-to-2008/>) published on April 14, 2016 to adjust for inflation and calculate the cumulative inflation rate through March 2016. The Consumer Price Index (CPI) and inflation for April 2016 is scheduled for release by the United States government on May 17, 2016. (See a chart of recent inflation rates (<http://www.usinflationcalculator.com/inflation/current-inflation-rates/>)).

INFLATION ([HTTP://WWW.USINFLATIONCALCULATOR.COM/CATEGORY/INFLATION/](http://www.usinflationcalculator.com/category/inflation/))

US Inflation Climbs in March, Annual Inflation Rate Eases Again

(<http://www.usinflationcalculator.com/inflation/us-inflation-climbs-in-march-annual-inflation-rate-eases-again/10001967/>)

APRIL 14, 2016 ([HTTP://WWW.USINFLATIONCALCULATOR.COM/INFLATION/US-INFLATION-CLIMBS-IN-MARCH-ANNUAL-INFLATION-RATE-EASES-AGAIN/10001967/](http://www.usinflationcalculator.com/inflation/us-inflation-climbs-in-march-annual-inflation-rate-eases-again/10001967/)) | LEAVE A COMMENT ([HTTP://WWW.USINFLATIONCALCULATOR.COM/INFLATION/US-INFLATION-CLIMBS-IN-MARCH-ANNUAL-INFLATION-RATE-EASES-AGAIN/10001967/#RESPOND](http://www.usinflationcalculator.com/inflation/us-inflation-climbs-in-march-annual-inflation-rate-eases-again/10001967/#RESPOND))

The cost of living in the United States increased in March for the first time in four months, according to a government report released on Thursday, April 14. At the same time, underlying inflation rose less than forecast after rising more than expected in February.

Consumers spent less at grocery and clothing stores but more for healthcare, transportation and shelter. In addition and for the first time since November, drivers paid more to fill up their tanks.

Important Facts for State Policymakers

Deficit Reduction Act

January 8, 2008

Transfer of Assets in the Medicaid Program

The Deficit Reduction Act of 2005 introduced new rules that discourage the improper transfer of assets to gain Medicaid eligibility and receive long-term care services.

Background

The Medicaid program provides coverage for long-term care services for individuals who are unable to afford it. Some individuals, with assistance from financial planners and attorneys, have found ways of arranging assets so that they are preserved for the individual and/or family members, but are not countable when Medicaid eligibility is determined. In order to ensure the availability of long-term care services for people that truly need them, the Deficit Reduction Act of 2005 (DRA) addresses key areas related to transfers of assets for less than fair market value. Tightening Medicaid asset transfer rules discourages the use of such "Medicaid planning" techniques and makes it more difficult for individuals with the resources to pay for their own long-term care services to inappropriately transfer assets in order to qualify for Medicaid. These key areas are: asset review "look-back" periods; asset transfer penalty periods; the treatment of annuities; life estates; notes and loans; the "income first" rule; excluded coverage for substantial home equity; and Continuing Care Retirement Community deposits.

Key Transfer of Asset Provisions in the DRA

Extension of Look-Back Period and Beginning Date of Penalty Period

When an individual applies for Medicaid coverage for long-term care, States conduct a review, or "look-back," to determine whether the individual (or his or her spouse) transferred assets (e.g., cash gifts to children, transferring home ownership) to another person or party for less than fair market value (FMV). The DRA lengthened the "look-back period" to 60 months (five years) prior to the date the individual applied for Medicaid.

When individuals transfer assets at less than FMV they are subject to a penalty that delays the date they can qualify to receive Medicaid long-term care services. Previously the penalty period began with the month the assets were transferred. This provided an opportunity for individuals to avoid part or all of a penalty by transferring assets months or years before they actually entered a nursing home. Under the DRA, the penalty period, for transfers made on or after February 8, 2006, now begins on either the date of the asset transfer, or the date the individual enters a nursing home and is found eligible for coverage of institutional level services that Medicaid would pay for were it not for the imposition of a transfer penalty—whichever is later.

Treatment of Annuities

Prior to the DRA, annuities were often used to shelter assets, especially in situations where one member of a couple entered a nursing home. To discourage the use of annuities to shelter funds for heirs while qualifying for Medicaid long-term care services, the DRA changed the treatment of annuities. As a condition of eligibility for coverage of long-term care services, Medicaid applicants are now required to

disclose any interest in an annuity. Also, annuities must name the State as the primary remainder beneficiary (or as the second remainder beneficiary after a community-based spouse or minor or disabled child) for at least the value of the Medicaid assistance provided. If the annuity does not name the State as a remainder beneficiary in the proper position, the annuity must be treated as a transfer of assets for less than fair market value. The full purchase price of the annuity is the amount that is subject to penalty.

Annuities purchased by or on the behalf of an individual who applied for Medicaid coverage for long-term care shall be treated as an asset transfer for less than FMV unless the annuity meets certain requirements pertaining to retire plans as set forth in the Internal Revenue Service code, or unless the annuity is irrevocable, non-assignable, actuarially sound, and provides for payments in equal amounts during the term of the annuity, with no deferral and no balloon payments.

Life Estates

Under a typical life estate, an individual transfers ownership of his or her own home or other property to another person; for example a son or daughter, but retains a right to live in the home for the remainder of the individual's life. However, some individuals have used this planning mechanism to purchase a life estate in another person's home, but without intending to ever reside in that home. This type of life estate transaction is really just an attempt to transfer assets for less than fair market value to someone else. To prevent this, the DRA requires that the purchase of a life estate interest in another person's home be treated as a transfer of assets for less than FMV unless the purchaser actually lives in the home for at least one year after the date of purchase. Additionally, even if the individual lives in the home for at least one year, if the purchase amount of the life estate is greater than the computed value of the life estate's interest, the difference is considered a transfer for less than fair market value that may be subject to penalty.

Note and Loans

The DRA requires that States now consider the purchase of a promissory note, loan or mortgage as a transfer of assets for less than fair market value, and thus subject to penalty, unless the following conditions are met: (1) the repayment terms are actuarially sound; (2) payments are made in equal amounts with no balloon payments; and, (3) the note, loan or mortgage prohibits cancellation of the debt upon the death of the lender.

*** Waiver of Imposition of Transfers of Assets Penalties in Cases of Undue Hardship**

The DRA established a hardship waiver that permits States to make an exception to a transfer of assets penalty in cases where imposition of a penalty would threaten the health or life of an individual, or when the application of a penalty would deprive the individual of food, clothing, shelter or other necessities of life. The DRA also allows a long-term care facility to apply for an undue hardship waiver on behalf of a resident, provided the facility has the resident's consent. Finally, the DRA provides an option under which States can elect to pay for a person's nursing home care for up to 30 days pending the outcome of a request for an undue hardship waiver.

Mandatory “Income First” Rule

The “income first rule” applies when determining whether to allocate additional resources to the community spouse to bring that spouse’s income up to the minimum monthly maintenance needs allowance under the Medicaid spousal impoverishment provisions. The DRA requires States to first assume that all income that could be allocated from the institutionalized spouse to the community spouse has been allocated to that spouse before allocating any additional resources. More than half of the States already applied this rule before enactment of the DRA.

Excluded Coverage for Substantial Home Equity

The DRA requires States not to pay for Medicaid long-term care services for an individual whose equity interest in his or her home exceeds a certain level. The home equity cut-off is \$500,000, but States can elect to increase that amount up to \$750,000. There is an exception to this requirement for individuals with a spouse or a minor or blind or disabled child residing in the home. Also, States can elect not to apply this provision in cases of documented hardship.

Deposits with Continuing Care Retirement Communities

Continuing Care Retirement Communities, or CCRCs, typically provide a continuum of care ranging from independent residential living to nursing home care. Often CCRCs require an entrance deposit, which can be substantial. These entrance deposits typically are placed in an escrow account. Previously, these funds or deposits were excluded from a person’s countable resources when determining Medicaid eligibility because they could not be accessed by the applicant. The DRA requires States to consider these funds as countable resources when determining eligibility for Medicaid, provided (1) the funds can be used to pay for care under the terms of the individual’s contract with the facility should other resources of the individual be insufficient; (2) the entrance fee (or remaining portion) is refundable when the individual dies or elects to leave the CCRC; and (3) the entrance fee confers no ownership interest in the community.

State Action

In order to comply with the updated and new provisions relating to the transfer of asset review prior to the determination of an individual’s eligibility to receiving Medicaid long-term care service, States must make the necessary changes to their existing Medicaid State Plan.

Important Links

State Medicaid Directors Letter and Enclosure on DRA § 6011 - 6016

<http://www.cms.hhs.gov/smdl/downloads/SMD072706b.pdf>

<http://www.cms.hhs.gov/smdl/downloads/TOAEnclosure.pdf>

▶ Appeals vs. Undue Hardship Waivers

Appeals:

- An applicant/recipient has the fundamental right to appeal the Department's decision to deny, suspend or discontinue benefits.
- An appeal exists when there is disagreement surrounding establishment of the penalty period; whether fair consideration was received or the monetary amount of assets transferred without receiving fair consideration.

Undue Hardship Waivers:

- Individuals determined ineligible for payment of LTC due to asset transfers or excess home equity may choose to apply for an undue hardship waiver.
- An undue hardship exists when denial of payment of LTC would:
 - deprive the individual of medical care, endangering the person's health or life; or
 - Deprive the individual of food, shelter or other basic necessities of life.

*

Tom Corbett, Governor
Beverly Mackereth, Secretary

- (c) Effective/applicability date.
- § 1.529A-2 Qualified ABLE program.**
- (a) In general.
- (b) Established and maintained by a State or agency or instrumentality of a State.
- (1) Established.
- (2) Maintained.
- (3) Community Development Financial Institutions (CDFIs).
- (c) Establishment of an ABLE account.
- (1) In general.
- (2) Only one ABLE account.
- (3) Beneficial interest.
- (d) Eligible individual.
- (1) In general.
- (2) Frequency of recertification.
- (3) Loss of qualification as an eligible individual.
- (e) Disability certification.
- (1) In general.
- (2) Marked and severe functional limitations.
- (3) Compassionate allowance list.
- (4) Additional guidance.
- (5) Restriction on use of certification.
- (f) Change of designated beneficiary.
- (g) Contributions.
- (1) Permissible property.
- (2) Annual contributions limit.
- (3) Cumulative limit.
- (4) Return of excess contributions and excess aggregate contributions.
- (h) Qualified disability expenses.
- (1) In general.
- (2) Example.
- (i) Separate accounting.
- (j) Program-to-program transfers.
- (k) Carryover of attributes.
- (l) Investment direction.
- (m) No pledging of interest as security.
- (n) No sale or exchange.
- (o) Change of residence.
- (p) Post-death payments.
- (q) Reporting requirements.
- (r) Effective/applicability date.

§ 1.529A-3 Tax treatment.

- (a) Taxation of distributions.
- (b) Additional exclusions from gross income.
- (1) Rollover.
- (2) Program-to-program transfers.
- (3) Change in designated beneficiary.
- (4) Payments to creditors post-death.
- (c) Computation of earnings.
- (d) Additional tax on amounts includible in gross income.
- (1) In general.
- (2) Exceptions.
- (e) Tax on excess contributions.
- (f) Filing requirements.
- (g) Effective/applicability date.

§ 1.529A-4 Gift, estate, and generation-skipping transfer taxes.

- (a) Contributions.

- (1) In general.
- (2) Generation-skipping transfer (GST) tax.
- (3) Designated beneficiary as contributor.
- (b) Distributions.
- (c) Change of designated beneficiary.
- (d) Transfer tax on death of designated beneficiary.
- (e) Effective/applicability date.

§ 1.529A-5 Reporting of the establishment of and contributions to an ABLE account.

- (a) In general.
- (b) Additional definitions.
- (1) Filer.
- (2) TIN.
- (c) Requirement to file return.
- (1) Form of return.
- (2) Information included on return.
- (3) Time and manner of filing return.
- (d) Requirement to furnish statement.
- (1) In general.
- (2) Time and manner of furnishing statement.
- (3) Copy of Form 5498-QA.
- (e) Request for TIN of designated beneficiary.
- (f) Penalties.
- (1) Failure to file return.
- (2) Failure to furnish TIN.
- (g) Effective/applicability date.

§ 1.529A-6 Reporting of distributions from and termination of an ABLE account.

- (a) In general.
- (b) Requirement to file return.
- (1) Form of return.
- (2) Information included on return.
- (3) Time and manner of filing return.
- (c) Requirement to furnish statement.
- (1) In general.
- (2) Time and manner of furnishing statement.
- (3) Copy of Form 1099-QA.
- (d) Request for TIN of contributor(s).
- (e) Penalties.
- (1) Failure to file return.
- (2) Failure to furnish TIN.
- (f) Effective/applicability date.

§ 1.529A-7 Electronic furnishing of statements to designated beneficiaries and contributors.

- (a) Electronic furnishing of statements.
- (1) In general.
- (2) Consent.
- (3) Required disclosures.
- (4) Format.
- (5) Notice.
- (6) Access period.
- (b) Effective/applicability date.

§ 1.529A-1 Exempt status of qualified ABLE program and definitions.

- (a) *In general.* A qualified ABLE program described in section 529A is exempt from income tax, except for the tax imposed under section 511 on the

unrelated business taxable income of that program.

(b) *Definitions.* For purposes of section 529A, this section and §§ 1.529A-2 through 1.529A-7—

(1) *ABLE account* means an account established under a qualified ABLE program and owned by the designated beneficiary of that account.

(2) *Contracting State* means a State without a qualified ABLE program of its own, which, in order to make ABLE accounts available to its residents who are eligible individuals, contracts with another State having such a program.

(3) *Contribution* means any payment directly allocated to an ABLE account for the benefit of a designated beneficiary.

(4) *Designated beneficiary* means the individual who is the owner of the ABLE account and who either established the account at a time when he or she was an eligible individual or who has succeeded the former designated beneficiary in that capacity (successor designated beneficiary). If the designated beneficiary is not able to exercise signature authority over his or her ABLE account or chooses to establish an ABLE account but not exercise signature authority, references to the designated beneficiary with respect to his or her actions include actions by the designated beneficiary's agent under a power of attorney or, if none, a parent or legal guardian of the designated beneficiary.

(5) *Disability certification* means a certification deemed sufficient by the Secretary to establish a certain level of physical or mental impairment that meets the requirements described in § 1.529A-2(e).

(6) *Distribution* means any payment from an ABLE account. A *program-to-program transfer* is not a distribution.

(7) *Earnings* attributable to an account are the excess of the total account balance on a particular date over the *investment in the account* as of that date.

(8) *Earnings ratio* means the amount of earnings attributable to the account as of the last day of the calendar year in which the designated beneficiary's taxable year begins, divided by the total account balance on that same date, after taking into account all distributions made during that calendar year and all contributions received during that same year other than those (if any) returned in accordance with § 1.529A-2(g)(4).

(9) *Eligible individual* for a taxable year means an individual who either:

(i) Is entitled during that taxable year to benefits based on blindness or disability under title II or XVI of the Social Security Act, provided that such

designated beneficiary in maintaining or improving his or her health, independence, or quality of life. Such expenses include, but are not limited to, expenses for education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight and monitoring, funeral and burial expenses, and other expenses that may be identified from time to time in future guidance published in the Internal Revenue Bulletin. As previously stated, expenses incurred at a time when a designated beneficiary is neither disabled nor blind within the meaning of the proposed regulations are not qualified disability expenses.

In order to implement the legislative purpose of assisting eligible individuals in maintaining or improving their health, independence, or quality of life, the Treasury Department and the IRS conclude that the term "qualified disability expenses" should be broadly construed to permit the inclusion of basic living expenses and should not be limited to expenses for items for which there is a medical necessity or which provide no benefits to others in addition to the benefit to the eligible individual. For example, expenses for common items such as smart phones could be considered qualified disability expenses if they are an effective and safe communication or navigation aid for a child with autism. The Treasury Department and the IRS request comments regarding what types of expenses should be considered qualified disability expenses and under what circumstances. The proposed regulations authorize the identification of additional types of qualified disability expenses in guidance published in the Internal Revenue Bulletin. See § 601.601(d)(2). A qualified ABLE program must establish safeguards to distinguish between distributions used for the payment of qualified disability expenses and other distributions, and to permit the identification of the amounts distributed for housing expenses as that term is defined for purposes of the Supplemental Security Income program of the Social Security Administration.

Limitation on Number of ABLE Accounts of a Designated Beneficiary

Section 529A(c)(4) generally provides that, except with respect to certain rollovers, once an ABLE account has been established for a designated beneficiary, no account subsequently established for that same designated

beneficiary may qualify as an ABLE account. The proposed regulations provide that, except with respect to rollovers and program-to-program transfers, no designated beneficiary may have more than one ABLE account in existence at the same time, but provides that a prior ABLE account that has been closed does not prohibit the subsequent creation of another ABLE account for the same designated beneficiary. A qualified ABLE program must obtain a verification from the eligible individual, signed under penalties of perjury, that he or she has no other ABLE account (except in the case of a rollover or program-to-program transfer). The proposed regulations provide that, in the event that any additional ABLE account is opened for a designated beneficiary with an ABLE account already in existence, only the first such account created for that designated beneficiary qualifies as an ABLE account, and each other account is treated for all purposes as being an account of the designated beneficiary that is not an ABLE account under a qualified ABLE program. The proposed regulations also provide, however, that a return, in accordance with the rules that apply to returns of excess contributions and excess aggregate contributions under § 1.529A-2(g)(4), of the entire balance of a second or other subsequent account received by the contributor(s) on or before the due date (including extensions) for filing the designated beneficiary's income tax return for the year in which the account was opened and contributions to the second or subsequent account were made will not be treated as a gift or distribution to the designated beneficiary for purposes of section 529A.

The prohibition of multiple ABLE accounts, however, does not apply to prevent a timely rollover or program-to-program transfer of the designated beneficiary's account to an ABLE account under a different qualified ABLE program.

Residency Requirements

Consistent with section 529A(b)(1)(C), the proposed regulations require that an ABLE account for a designated beneficiary may be established only under the qualified ABLE program of the State in which that designated beneficiary is a resident or with which the State of the designated beneficiary's residence has contracted for the provision of ABLE accounts. If a State does not establish and maintain a qualified ABLE program, it may contract with another State to provide an ABLE program for its residents. The statute is

silent as to whether a designated beneficiary must move his or her existing ABLE account when the designated beneficiary changes his or her residence. The Treasury Department and the IRS are concerned about imposing undue administrative burdens and costs on designated beneficiaries who frequently change State residency, such as members of military families. Therefore, the proposed regulations provide that a qualified ABLE program may permit a designated beneficiary to continue to maintain his or her ABLE account that was created in that State, even after the designated beneficiary is no longer a resident of that State. However, in order to enforce the one ABLE account limitation and in accordance with section 529A(g)(1), the proposed regulations provide that, other than in the case of a rollover or a program-to-program transfer of a designated beneficiary's ABLE account, a qualified ABLE program must require the designated beneficiary to verify, under penalties of perjury, when creating an ABLE account that the account being established is the designated beneficiary's only ABLE account. For example, the eligible individual could be required to check a box providing such verification on a form used to establish the account. The Treasury Department and the IRS are concerned that without such safeguards individuals could inadvertently establish two accounts with adverse tax consequences due to the loss of ABLE account status for the second account and expect qualified ABLE programs to establish safeguards to ensure that the required limit of one ABLE account per designated beneficiary is not violated.

Investment Direction

Section 529A(b)(4) states that a program shall not be treated as a qualified ABLE program unless it provides that the designated beneficiary may directly or indirectly direct the investment of any contributions to the program or any earnings thereon no more than two times in any calendar year. A program will not violate this requirement merely because it permits a designated beneficiary or a person with signature authority over a designated beneficiary's account to serve as one of the program's board members or employees, or as a board member or employee of a contractor that the program hires to perform administrative services.

Cap on Contributions

Section 529A(b)(6) provides that a qualified ABLE program must provide adequate safeguards to prevent aggregate

disabilityscoop

ABLE Accounts May Be Available Sooner Than Expected

by Michelle Diamant | January 11, 2016

A tweak to federal law is poised to greatly expand choice and speed up availability of accounts allowing people with disabilities to save money without risking their government benefits.

Tucked inside a tax bill approved by lawmakers last month is a provision that will permit individuals with disabilities to open new accounts established under the Achieving a Better Life Experience, or ABLE, Act in any state, regardless of where they reside. *

The change means that people with disabilities across the country will be able to open ABLE accounts when the first state programs are up and running which could happen as soon as February or March, advocates say.

With the new accounts, people with disabilities will for the first time be able to accrue up to \$100,000 in savings without losing access to Social Security and other government benefits. Medicaid coverage will remain intact no matter how much money is saved in an individual's ABLE account.

Despite federal passage of the ABLE Act in 2014, states had to approve their own legislation and develop mechanisms to regulate and administer the new accounts before letting consumers take advantage. So far, 35 states have approved such legislation, advocates say, but some are farther along than others in implementing programs.

"Some of the smaller states don't have the capacity to create an ABLE program so this will allow more people with disabilities to access ABLE accounts and access ABLE accounts faster," said Sara Hart Weir, president of the National Down Syndrome Society.

Without the recent legislative change, individuals with disabilities would have been limited by the timetable and specific offerings in their state. Now, families will be able to shop around to find the state program that best suits their needs and the

availability of many options should promote competition among states to make their programs attractive, according to Chris Rodriguez of the National Disability Institute.

It's likely that each state ABLE program will only work with one or a handful of financial institutions and fees may vary, so enabling families to access programs across state lines will dramatically increase their options, Rodriguez said.

Some states are already working to encourage residents to utilize in-state accounts by offering tax incentives, he said.

"It's a pretty exciting development," Rodriguez said of the federal provision allowing consumers to access accounts originating in any state. "I know it's shaking things up. Some of the states are looking to quicken their development and others are sitting back and looking at whether they need to build a program."

Ohio, Florida, Virginia and Nebraska are widely expected to be among the first to make ABLE programs available. Accounts are likely to be created and administered through dedicated state websites, advocates say.

To be eligible for an ABLE account, an individual must have a disability that originated before the age of 26.

Funds in the accounts can be used to pay for education, health care, transportation, housing and other expenses. Interest earned on savings in the accounts will be tax-free.

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View this article online at <https://www.disabilityscoop.com/2016/01/11/able-accounts-sooner-expected/21752/>

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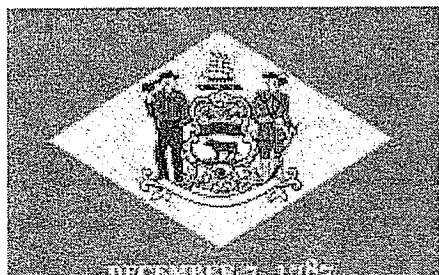
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Last updated: April 11, 2016

Distracted driving update: State Rep. Debra Hudson seeks to double the fines for electronic distracted driving. Her House Bill 302 of 2016 also calls for demerit points vs. the driver's license for texting or using a handheld cell phone. Delaware's base fines would increase from \$50 to \$100, with serial offenders paying as much as \$300, up from \$100 to \$200.



"Currently many drivers, particularly novice drivers, ignore the laws prohibiting texting and handheld-

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DISTRACTED DRIVING NEWS UPDATES

Tenn. targets distracted school bus drivers: Tennessee "now has the strongest law in the nation" guarding aga...

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Tennessee: Senate OKs making texting & driving a moving violation. Bill back to House on issue of how many points. <https://t.co/KUIbAZcXnY> April 20, 2016 12:36 am

Alaska moving texting & driving out of courts: Alaska is reining in its texting & driving law in order to enco...

<https://t.co/ve3xKFA0Em> April 19, 2016 1:46 am

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phone use while driving," the proposal says. Younger drivers seem "to be oblivious to some types of authority" and need stronger disincentives to stay away from their electronic devices while behind the wheel, Hudson says. The measure is backed by AAA Mid-Atlantic. The House approved an increase in distracted driving fines in 2014 but the legislation did not make it out of the Senate.

Current prohibitions:

- Text messaging prohibited for all drivers.
- Handheld cell phone use and use of Web prohibited for all drivers — hands-free devices OK. Includes PDAs, paging devices, games, laptops.
- Drivers with learner’s permits prohibited from using cell phones.
- School bus operators prohibited from using cell phones while driving.

Fines: \$106 (out of pocket, first offense), then up to \$300 (source OHS). Base fine \$50 first offense and \$100 to \$200 after that.

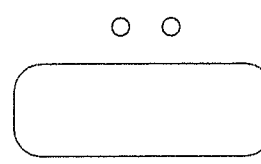
Read the laws: [Texting & mobile phones](#) | [School bus drivers](#)

Distracted driving legislation (2016):

House Bill 302: Would increase base fine for electronic distracted driving to \$100 (first offense) and then \$200 to \$300. Would establish demerit points vs. license for serial offenders. (Hudson)

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Distracted driving notes (2016):

HB 302's backers in the Senate are state Sen. Karen Peterson and Sen. Bryan Townsend.

2014 distracted driving legislation:

House Bill 298: Would hike the base fine for a first offense for using a handheld cell phone or other electronic device while driving from \$50 to \$75. Approved by the Public Safety Committee on April 30. Approved by the full House in a unanimous vote of June 12. Died in Senate committee. (Miro)

HB 155: Would bar drivers from using a wearable computer with head-mounted display, such as Google Glass. Cleared by the Public Safety Committee on June 12. (Baumbach)

House Resolution 28: Recognizes April 2014 as Distracted Driving Awareness Month. Approved by House in April 10 voice vote. (Short)

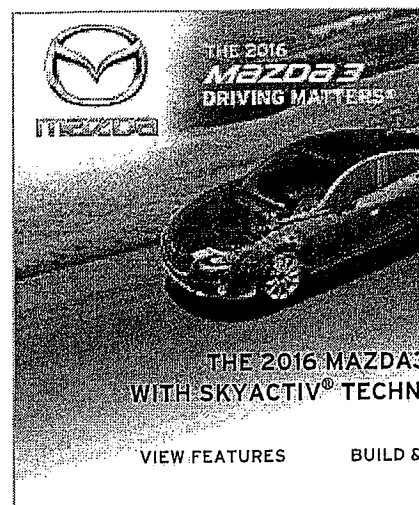
2014 distracted driving notes:

The House voted unanimously to raise the fine for electronic distracted driving to \$75. The increase would apply to first-time offenders. Fines for serial offenses would remain at \$100 to \$200. The 2014 bill comes from Republican state Rep. Joe Miro.

Another 2014 distracted driving bill seeks to bar drivers from wearing Google Glass.

2013 distracted driving notes:

Delaware law enforcement wrote about 19,500 citations for electronic distracted driving in 2013. Almost 150



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TOPICS

crashes in Delaware were blamed on distracted driving that year — about the same as in recent years.

Delaware law enforcement has issued over 33,000 cell phone citations since the cell phone law went into effect in 2011, state officials said June 21.

The federally funded “Phone in One Hand; Ticket in the Other” enforcement program has wrapped in Delaware, with more than 1,500 drivers stopped and cited in the third and final phase.

The total number of drivers ticketed under the three-part crackdown was 5,757, the Office of Highway Safety said June 21, 2013. Ticketing declined in both the second and third crackdowns.

The third sweep ran June 4-17, with at least 1,562 citations issued. In phase 2, April 9-22, law officers ticketed 2,043 distracted drivers. In November’s first phase, 2,152 distracted drivers were cited statewide, the OHS said.

“Preliminary evidence suggests that the program is having the desired effect on reducing hand held cell phone use while driving,” said Jana Simpler, director of the Office of Highway Safety. “We believe motorists heard our message loud and clear.”

More than 40 law enforcement agencies in Delaware targeted drivers who were texting or using handheld cell phones.

Sacramento also received funding this round, with 2,923 drivers cited Nov. 30-Dec. 9, 2012. The combination of

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Columbia distracted driving news

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increased enforcement and media awareness campaigns are similar to those undertaken in 2011 in Hartford, Ct., and Syracuse, N.Y.

Law officers in Delaware handed out 13,142 tickets for handheld cell phone use in 2012, the Office of Highway Safety said in April. Distracted driving was a factor in 125 crashes during the year, the Office of Highway Safety said.

OHS director Jana Simpler said after April's distracted driving sweep: "While we are seeing our message get through to Delaware drivers, our approach remains the same: If you are caught texting or using a hand-held device while driving, you will be stopped and ticketed." The U.S. DOT provided \$900,000 to expand the state's pilot enforcement campaign.

2013 legislation:

No distracted driving bills were filed for the 2013 General Assembly session.

2012 legislation:

House Bill 294: Requires that commercial drivers who violate the electronic distracted driving laws have the offense posted on their driving records. This brings Delaware state law into compliance with the FMCSA regulations regarding electronic communications devices and commercial drivers. Approved by the House in a unanimous vote April 26. Approved by the full Senate in a 14-3 vote of June 21. Signed by the governor June 28. (Mitchell)

House Resolution 38: Encourages compliance with state driving laws regarding electronic handheld devices. Calls

on the cell phone and automobile industries to continue distracted driving awareness campaigns, and to develop devices that limit use of cell phones by drivers. Approved by House on March 28 and by the Senate on March 29. Non-binding. (Willis)

2011-2012 distracted driving notes:

Lewis Schiliro, Delaware secretary of Safety and Homeland Security, said some police agencies “made an average of more than one arrest an hour” during the federally funded two-week distracted driving crackdown that began Nov. 7, 2012. The ticketing “will offer a tough lesson to any driver caught paying attention to their phones instead of the road,” Schiliro said.

David Strickland, head of the National Highway Traffic Safety Administration, said the distracted driving crackdown funded in Delaware uses “a proven formula.” In Hartford, Ct., a similar sweep resulted in a 72 percent drop in texting by drivers, he said. U.S. Transportation Secretary Ray LaHood unveiled the Delaware program as part of his “Blueprint for Ending Distracted Driving.” California also is receiving funding.

About 17,100 tickets have been issued since Delaware’s electronic distracted driving laws took effect in January 2011, State Police say. There were 9,842 tickets issued in 2011 and 7,284 so far in 2012 (as of August), Sgt. Paul Shavack told Hands Free Info. Fines range from \$50 to \$200.

At least 139 crashes in 2011 were caused in part by distracted drivers, state safety officials say.

Rep. Joe Miro, R-Pike Creek, who pushed through the Delaware talking & texting law, says one reason for all those distracted driving citations is ignorance of the law: "I think we need to be a little more aggressive in reminding drivers that it is the law."

The General Assembly is concerned as well. It has called on state drivers to observe state electronic distracted driving laws. The resolution of March 2012 also sought more distracted driving prevention efforts by the mobile phone and auto industries.

The governor has signed legislation that brings the state into compliance with federal regulations concerning reporting of commercial driver violations of wireless electronic communications laws. House Bill 294 got the final OK in late June.

Delaware State Police conducted a driver safety crackdown just before the 2012 Memorial Day weekend and the 2011 New Year's week, looking for distracted drivers and motorists who are under the influence.

The state's one-day crackdown on handheld cell phone violations yielded 330 tickets April 21, 2011. The sweep was conducted as part of Distracted Driving Awareness Month.

Miss Delaware Maria Cahill's "platform" for the Miss America pageant is auto safety, with the focus on texting while driving. Cahill's college roommate died in a texting-related crash.

2010 legislation:

House Substitute 1 for HB 229: Bans text messaging,

handheld cell phone use and Internet activities. Includes PDAs, paging devices, games, laptops. Applies when vehicle is in motion. Primary enforcement. Fines \$50 (first offense)/\$100/\$200. Cleared the House public safety committee on March 17. Approved by the full House on May 13 in a 33-5 vote. Approved by the Senate on June 15 by a 18-3 vote. Approved again by the House (and finalized) on June 22 in a 34-6 vote. Signed by Gov. Jack Markell on July 6. **Latest action:** Enforcement began Jan. 2, 2010. (Scott, Miro)

HB 298: Would prohibit the use of handheld cell phones by a driver while the vehicle is in motion. Fines \$50/\$100. (Miro)

2010 legislation notes:

Distracted driving was a contributor to 139 crashes in 2010, state officials said.

Several amendments were added to House Substitute 1 for HB 229 before it was approved May 13 in the House. One allows drivers to use their hands to enter numbers for a phone call or to engage hands-free accessories. The other exempts farm tractors and trucks from the ban on handheld electronics.

Rep. Darryl M. Scott, Dover, introduced the substitute for his HB 229 (of 2009) that watered down its proposed ban on all cell phone use by drivers to allow for hands-free operation. "I basically found I did not have support for a complete ban on cell phones," he said Feb. 8. An ally amended HB 229 to make it a "handheld cell phone" ban.

2009 legislation:

HB 40 Substitute (HS1): Would ban text messaging while

driving. Primary enforcement. \$50 fine. Tabled by sponsor on May 12, 2009, due to House opposition and problems with wording. Reintroduced as a text-messaging bill, HS1 for HB 40. That bill (without handheld cell phone provisions) was approved by the Delaware House on May 14 and sent to the Senate. Out of Public Safety Committee "on its merits" on June 18. (Miro)

HB 229: Would have prohibited all cell phone use by drivers. Amended to allow for hands-free operation of a cell phone by drivers in January 2010. (Scott)

Legislation notes:

The new bill, HS1 for HB 40, calls for a maximum \$50 fine and violations will be treated as a primary offense, meaning police can pull over drivers they believe to be text messaging. It also seeks to overrule all local and regional legislation.

The original HB 40 was presented by Rep. Joseph E. Miro, R-Pike Creek Valley. "I am very disappointed we are not passing the entire bill," Miro told the News Journal. "I will come back with the other half that is missing from this legislation sometime in the future, but for now, this is the best we can do."

As a cell phone and texting bill, HB 40 had been a magnet for amendments concerning exceptions such as use of ham-radio communications and work-related walkie-talkies.

While still a handheld cell phone ban, HB 40 required only that drivers have a hands-free device in order to drive and use a cell phone. It did not require drivers to

use the attachment. It also allowed for the reading of text messages, another problem fixed by amendments.

Wilmington, the largest city in Delaware, has approved a ban on the use of handheld cell phones and text messaging devices while driving. These activities would be considered primary offenses, meaning police could pull over drivers for that reason alone. Fines under the plan, presented by Michael Brown Sr., would run \$50. "Whatever Dover does or doesn't do, we need to take steps here to try to save lives when we can," Brown said. The ban takes effect Jan. 1, 2009.

Rep. Miro combined two bills that failed in the 2008 session to forge the 2009 legislation HB 40. "I brought this back because it is very close to my heart and I really think we need to address the issue," Miro said.

Miro's efforts to limit cell phone use by drivers date back to 2001.

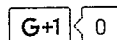
When a Miro bill (HB78) seeking to require hands-free devices for drivers was defeated in May 2007, it brought the following reaction:

"Why do we need this legislation?" said Rep. Dennis P. Williams, D-Wilmington, a retired lawman.

"What about a cup of coffee (being a distraction)? What about a CD player or a radio?"

Delaware State Police report that cell phones were a factor in 252 traffic accidents in 2008.

Tweet





STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
MARGARET M. O'NEILL BUILDING
410 FEDERAL STREET, SUITE 1
DOVER, DE 19901

VOICE: (302) 739-3620
TTY/TDD: (302) 739-3699
FAX: (302) 739-6704

MEMORANDUM

DATE: May 29, 2014

TO: All Members of the Delaware State Senate
and House of Representatives

FROM: Ms. Daniese McMullin-Powell, *DM/P/so* Chairperson
State Council for Persons with Disabilities

RE: H.B. 298 (Distracted Driving Civil Penalty)

The State Council for Persons with Disabilities (SCPD) has reviewed H.B. 298 which would raise the fine for a first offense for using a hand-held cell phone or other electronic device while driving from \$50 to \$75. As background, the Delaware Code currently authorizes civil penalties for drivers using handheld phones and devices. A first offense results in a \$50 civil penalty. A subsequent offense results in a \$100-\$200 civil penalty. Consistent with the attached articles, police issued 19,610 citations for violations of the law in 2013. The State Office of Highway Safety reported there were 149 cellphone related crashes in Delaware in 2013. It is inferable that some of these crashes resulted in injuries resulting in disability. SCPD endorses the proposed legislation based on the following observations.

First, statistics on the dangers of use of handheld devices while driving are compelling. On April 10, 2014, the House passed H.R. 28 recognizing April as "Distracted Driving Awareness and Enforcement Month". The preamble to the legislation includes the following observations: 1) drivers using cell phones are 4 times more likely to be in a crash and miss seeing up to 50% of the roadway environment; 2) cell phone use is a factor in nearly 1 in 4 crashes; 3) sending or receiving a text takes a driver's eyes off the road for an average of 4.6 seconds, the equivalent of driving the length of a football field when traveling at 55 mph; and 4) the percentage of drivers visibly manipulating hand-held devices is increasing.

Second, according to the attached April 13 News Journal article, Delaware's penalties are lower than those in 34 of the 40 other states with laws banning texting or using handheld phones while driving.

Third, since the percentage of drivers using handheld devices continues to increase despite current laws, enhancing penalties may have a deterrent effect. A \$50 civil penalty is so modest that many

drivers will not be concerned with the consequences of violating the law. A higher penalty could be supported given the risk of accidents and resulting injuries attributable to distracted driving. In addition, the legislature may want to consider raising the fine for subsequent offenses.

Thank you for your consideration and please contact SCPD if you have any questions regarding our position or observations on the proposed legislation.

cc: The Honorable Jack Markell
Mr. Brian Hartman, Esq.
Governor's Advisory Council for Exceptional Citizens
Developmental Disabilities Council

HB 298 distracted driving civil penalty 5-29-14

One trick improves your driving in seconds

EYES ON THE ROAD JIM LARDEAR



Prepare to be shocked and amazed. Use this one trick to improve your driving in seconds: Turn off your cellphone and put it out of reach before starting to drive. Seems simple. Still,

during 2013, more than 19,600 drivers in Delaware were issued citations under Delaware's hand-held cellphone and text messaging ban. And that's on top of the 16,100 cited in 2012.

However, there are far worse risks than just a ticket.

The National Highway Traffic Safety Administration estimates that 3,328 people were killed and an estimated 421,000 were injured in distraction-related crashes in 2012.

These numbers are roughly 10 percent of all fatal and 17 percent of all injury crashes, and they likely are under-reported because of the difficulty in determining the role distraction plays in crashes.

Last year in Delaware, police reported 149 crashes related to distracted driving.

Distracted driving is a danger that motorists easily recognize on Delaware's roadways.

According to a AAA study, nearly 89 percent of respondents believed that a driver talking on a cellphone represents a somewhat or serious threat to their personal safety.

That proportion increases to 95 percent with regard to drivers text messaging or emailing behind the wheel, and drivers checking or updating social media.

Here's another weird fact: Motorists recognize that risk in other drivers — but not in themselves.

AAA found a distressing "do as I say, not as I do" attitude among drivers.

While 31 percent of drivers believe they are not distracted while talking on their cellphone and driving, 82 percent believe that others are distracted while doing the exact same thing.

Although obvious to see, the concern and danger is not just with drivers holding a cellphone.

Hands-free and voice-activated technology that allows drivers to text and talk while driving is still dangerous because, cognitively, the brain is distracted.

A research study the AAA Foundation for Traffic Safety released last summer debunked that common myth by proving that hands-free cellphone use is not risk-free.

Mental distractions exist even when drivers keep their hands on the wheel.

The AAA Foundation study measured brainwaves, eye movement and more, showing hands-free technology increased mental workload and cognitive distractions that can lead to a type of tunnel vision or inattentive blindness where motorists don't see potential hazards right in front of them.

There is no time like the present to begin limiting potentially dangerous mental distractions behind the wheel, as April has been designated Distracted Driving Awareness Month in Delaware.

Delaware is one of 43 states with text messaging bans for drivers of all ages, one of 12 states prohibiting drivers of all ages from using hand-held

cellphones while driving, and one of 37 states that ban cellphone use by novice drivers.

If a police officer observes a motorist using a hand-held device while driving, they can pull them over and give them a \$106 fine for the first offense. Multiple offenses could result in fines up to \$300.

To prevent distracted driving, motorists are urged to:

» Turn off electronic devices and put them out of reach before starting to drive.

» Be good role models for young drivers, and talk with your teens about responsible driving.

» Speak up when you are a passenger and your driver uses an electronic device while driving. Offer to make the call for the driver, so his or her full attention stays on the driving task.

» Always wear your seatbelt. Seatbelts are the best defense against other unsafe drivers.

Jim Lardear is director of public and government affairs for AAA Mid-Atlantic.

Lawmakers seek to increase some car texting fines

By Jon Offredo
The News Journal

A group of state lawmakers want to boost the fine for texting and using cellphones while driving by \$25.

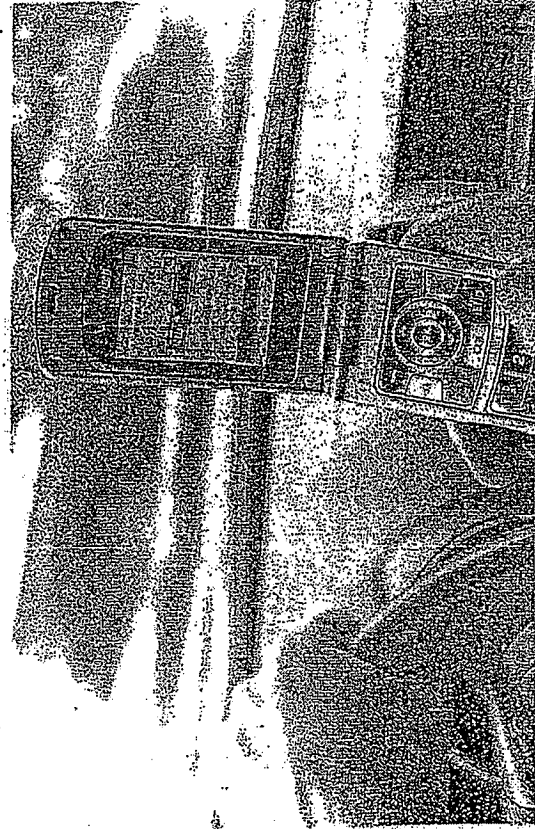
The legislation, introduced Thursday, raises the fine for first-time violators caught texting or using their hand-held device from \$50 to \$75.

"Talking while you are driving is not the issue, it is holding the phone while you're driving, or texting while you are driving. That is the issue," said Rep. Joe Miro, R-Pike Creek Valley.

"Cellphones have a place in our society. We're not trying to undermine that," he said on a phone interview Friday. Miro, the bill's sponsor, noted that he pulled over into a parking lot to speak since his hands-free device was not working.

State law bans texting while driving, and motorists are required to use hand-free technology when using cellphones in their vehicles. Officers who spot drivers using a hand-held device while driving will stop and cite them.

The bipartisan backed bill, which is



A bill introduced in the General Assembly on Thursday raises the fine for first-time violators caught texting or using their hand-held device from \$50 to \$75. AP

"Talking while you are driving is not the issue, it is holding the phone while you're driving, or texting while you are driving."

REP. JOE MIRO

since 2011.

Last year, there were 149 cellphone-related crashes in Delaware, according to an official with the state Office of Highway Safety.

Nationally, the U.S. Department of Transportation launched its first campaign and law enforcement crackdown to combat distracted driving. The campaign, which started last week, runs through April 15.

Police across the state were out in full force Friday as part of that campaign to ticket motorists using their cellphones while driving.

Contact Jon Offredo at (302) 678-4271 or at joffredo@delawareonline.com or on Twitter @jonoffredo

or using hand-held cellphones, while driving.

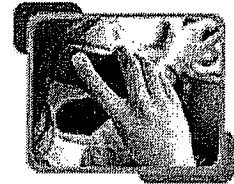
The state's texting and cell phone law first went into effect at the start of 2011. Police officers issued 19,610 citations for the offense last year, and about 35,000 other states with laws banning texting,

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Distracted Driving Laws

May 2016

This chart outlines state distracted driving laws. Some localities have additional regulations. Enforcement type is shown in parenthesis.



Hand-held Cell Phone Use: 14 states, D.C., Puerto Rico, Guam and the U.S. Virgin Islands prohibit all drivers from using hand-held cell phones while driving. All are **primary enforcement laws**—an officer may cite a driver for using a hand-held cell phone without any other traffic offense taking place.

All Cell Phone Use: No state bans all cell phone use for all drivers, but 38 states and D.C. ban all cell phone use by **novice drivers**, and 20 states and D.C. prohibit it for **school bus drivers**.

Text Messaging: Washington was the first state to pass a texting ban in 2007. Currently, 46 states, D.C., Puerto Rico, Guam and the U.S. Virgin Islands ban text messaging for all drivers. All but 5 have primary enforcement. Of the 4 states without an all driver texting ban:
 2 prohibit text messaging by **novice drivers**.

1 restricts **school bus drivers** from texting.

Crash Data Collection: Nearly all states include at least one category for distraction on police crash report forms, although the specific data collected varies. The Model Minimum Uniform Crash Criteria (MMUCC) guideline provides best practices on distraction data collection.

Preemption Laws: Some states have preemption laws that prohibit local jurisdictions from enacting their own distracted driving bans. States with such laws include – but may not be limited to – Florida, Iowa, Kentucky, Louisiana, Mississippi, Nevada, Pennsylvania, Oklahoma, Oregon and South Carolina.

NOTE: GHSA does not compile any additional data on distracted driving laws other than what is presented here. For more information, consult the appropriate State Highway Safety Office.

Learn More About Distracted Driving

- [Issue Brief](#)
- [Distracted Driving Publications](#)
- [State Media Campaigns](#)
- [Tips to Avoid Distractions](#)

State	All Cell Phone Ban			Text Messaging Ban			Crash Data
	Hand-held Ban	School Bus Drivers	Novice Drivers	All Drivers	School Bus Drivers	Novice Drivers	
Alabama			16, or 17 w/ Intermediate License <6 months (Primary)	Yes (Primary)	Covered under all driver ban		Yes
Alaska				Yes (Primary)	Covered under all driver ban		Yes
Arizona		Yes (Primary)					Yes
Arkansas ¹	18 - 20 years old (Primary)	Yes (Primary)	<18 (Secondary)	Yes (Primary)	Covered under all driver ban		Yes
California	Yes (Primary)	Yes (Primary)	<18 (Secondary)	Yes (Primary)	Covered under all driver ban		Yes
Colorado			<18 (Primary)	Yes (Primary)	Covered under all driver ban		Yes
Connecticut	Yes (Primary)	Yes (Primary)	<18 (Primary)	Yes (Primary)	Covered under all driver ban		
Delaware	Yes (Primary)	Yes (Primary)	Learner or Intermediate License (Primary)	Yes (Primary)	Covered under all driver ban		Yes
D.C.	Yes (Primary)	Yes (Primary)	Learners Permit (Primary)	Yes (Primary)	Covered under all driver ban		Yes
Florida				Yes (Secondary)	Covered under all driver ban		Yes
Georgia		Yes (Primary)	<18 (Primary)	Yes (Primary)	Covered under all driver ban		Yes
Guam	Yes (Primary)			Yes (Primary)	Covered under all driver ban		
Hawaii	Yes (Primary)		<18 (Primary)	Yes (Primary)	Covered under all driver ban		Yes

Idaho				Yes (Primary)	Covered under all driver ban	Yes
Illinois	Yes (Primary)	Yes (Primary)	<19 (Primary)	Yes (Primary)	Covered under all driver ban	Yes
Indiana			<21 (Primary) (eff. 7/2015)	Yes (Primary)	Covered under all driver ban	Yes
Iowa			Restricted or Intermediate License (Primary)	Yes (Secondary)	Covered under all driver ban	Yes
Kansas			Learner or Intermediate License (Primary)	Yes (Primary)	Covered under all driver ban	Yes
Kentucky		Yes (Primary)	<18 (Primary)	Yes (Primary)	Covered under all driver ban	Yes
Louisiana	Learner or Intermediate License (regardless of age)	Yes (Primary)	1st year of License (Primary for <18)	Yes (Primary)	Covered under all driver ban	Yes
Maine			Learner or Intermediate License (Primary)	Yes (Primary)	Covered under all driver ban	Yes
Maryland	Yes (Primary)		<18 (Primary)	Yes (Primary)	Covered under all driver ban	Yes
Massachusetts		Yes (Primary)	<18 (Primary)	Yes (Primary)	Covered under all driver ban	Yes
Michigan		Yes (Primary)	Level 1 or 2 License (Primary)	Yes (Primary)	Covered under all driver ban	Yes
Minnesota		Yes (Primary)	<18 w/ Learner or Provisional License (Primary)	Yes (Primary)	Covered under all driver ban	Yes
Mississippi		Yes (Primary)		Yes (Primary)	Covered under all driver ban	Yes
Missouri					<21 (Primary)	Yes
Montana						Yes
Nebraska			<18 w/ Learner or Intermediate License (Secondary)	Yes (Secondary)	Covered under all driver ban	Yes
Nevada	Yes (Primary)			Yes (Primary)	Covered under all driver ban	Yes
New Hampshire	Yes (Primary)		<18 (Primary)	Yes (Primary)	Covered under all driver ban	
New Jersey	Yes (Primary)	Yes (Primary)	Permit or Provisional License (Primary)	Yes (Primary)	Covered under all driver ban	Yes
New Mexico	In State vehicles		Learner or Provisional License (Primary)	Yes (Primary)	Covered under all driver ban	Yes
New York	Yes (Primary)			Yes (Primary)	Covered under all driver ban	Yes
North Carolina		Yes (Primary)	<18 (Primary)	Yes (Primary)	Covered under all driver ban	Yes
North Dakota			<18 (Primary)	Yes (Primary)	Covered under all driver ban	Yes
Ohio			<18 (Primary)	Yes (Secondary)	Covered under all driver ban	Yes
Oklahoma	Learner or Intermediate License (Primary)			Yes (Primary)	Covered under all driver ban	Yes
Oregon	Yes (Primary)		<18 (Primary)	Yes (Primary)	Covered under all driver ban	Yes
Pennsylvania				Yes (Primary)	Covered under all driver ban	Yes
Puerto Rico	Yes (Primary)			Yes (Primary)	Covered under all driver ban	
Rhode Island		Yes (Primary)	<18 (Primary)	Yes (Primary)	Covered under all driver ban	Yes
South Carolina					Covered under all driver ban	Yes

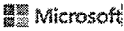
				Yes (Primary)			
<u>South Dakota</u>			Learner or Intermediate License (Secondary)	Yes (Secondary)	Covered under all driver ban		Yes
<u>Tennessee</u>		Yes (Primary)	Learner or Intermediate License (Primary)	Yes (Primary)	Covered under all driver ban		Yes
<u>Texas</u> ²		Yes, w/ passenger ≤17 (Primary)	<18 (Primary)		Yes, w/ passenger ≤17 (Primary)	<18 (Primary)	Yes
<u>Utah</u>		Yes (Primary)	<18 (Primary)	Yes (Primary)	Covered under all driver ban		Yes
<u>Vermont</u>	Yes (Primary)		<18 (Primary)	Yes (Primary)	Covered under all driver ban		Yes
<u>Virgin Islands</u>	Yes (Primary)			Yes (Primary)	Covered under all driver ban		Yes
<u>Virginia</u>		Yes (Primary)	<18 (Secondary)	Yes (Primary)	Covered under all driver ban		Yes
<u>Washington</u>	Yes (Primary)		Learner or Intermediate License (Primary)	Yes (Primary)	Covered under all driver ban		Yes
<u>West Virginia</u>	Yes (Primary)		<18 w/ Learner or Intermediate License (Primary)	Yes (Primary)	Covered under all driver ban		Yes
<u>Wisconsin</u>			Learner or Intermediate License (Primary)	Yes (Primary)	Covered under all driver ban		Yes
<u>Wyoming</u>				Yes (Primary)	Covered under all driver ban		Yes
Total States	14 + D.C. PR, Guam, Virgin Islands All Primary	20 + D.C. All Primary	38 + D.C. Primary (32 + D.C.) Secondary (6)	46 + D.C., PR, Guam, Virgin Islands Primary (41 + D.C., PR, Guam, Virgin Islands) Secondary (5)	1 Primary	2 Primary	48 + D.C., Virgin Islands

¹ Arkansas also bans the use of hand-held cell phones while driving in a school zone or in a highway construction zone. This law is secondarily enforced.

² Texas has banned the use of hand-held phones and texting in school zones.

Sources: [Insurance Institute for Highway Safety \(IIHS\)](#) and [State Highway Safety Offices](#).

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 phone 202.789.0942 , fax 202.789.0946, headquarters@ghsa.org


 Say goodbye to email servers and IT costs.

By DAVE JOHNSON / MONEYWATCH / November 6, 2013, 7:00 AM

The penalty for texting and driving in your state

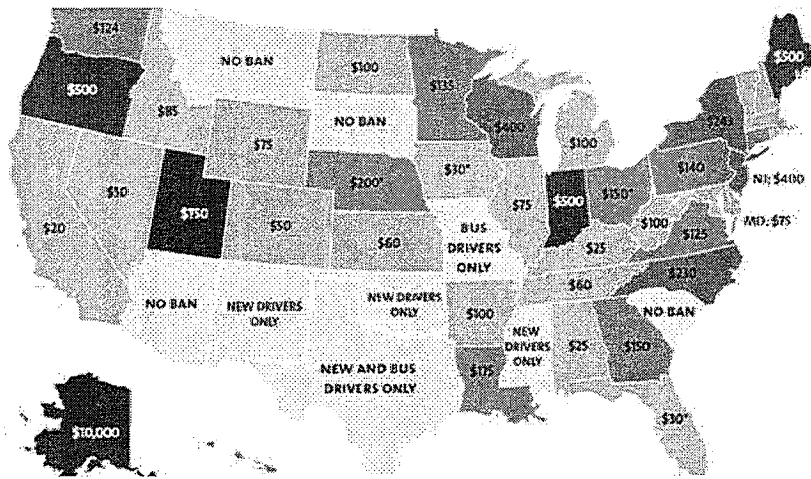


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(MoneyWatch) Do you text and drive, read email and drive, or instant message and drive? Hopefully not, but the fact remains that many people are doing it. In fact, a recent study from the Governors Voice on Highway Safety shows that more than a third of drivers are reading texts and emails while driving, and the percentage of accidents in which cell phone use plays a role continues to go up.

What will it take to keep you from becoming a statistic? Just knowing that it's dangerous is apparently not good enough. But what about paying a fine? Almost every state -- all but four -- have passed legislation banning texting while driving.

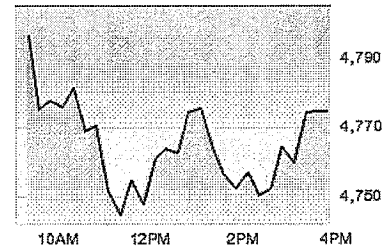
What's the penalty for using your phone for text or email while driving? It varies by state. Ignoring the four states which have enacted no laws, the lightest bill you can get is in California: Just \$20. That's in stark contrast to Alaska, which charges an incredible \$10,000 for texting while driving. New Jersey comes down somewhere in the middle, with a \$400 fee. You can see all the states in an infographic at Mother Jones, or browse this list, arranged from the most to the least costly states:

- Alaska \$10,000
- Utah \$750
- Guam \$500
- Indiana \$500
- Maine \$500

Market Data

Enter Ticker Symbol or Company Name

NASDAQ: May 01, 2016



Symbol	Last	Change	% Change
DOW	17,773.64	-57.12	-0.32%
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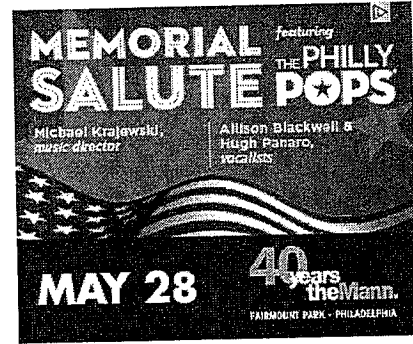
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Market News

HOUSE BILL 302

Fines for texting and driving may double



**DELAWARE
LEGISLATIVE SESSION
MATTHEW ALBRIGHT**

Getting caught texting while driving in Delaware could soon bring greater fines and driver's license points.

House Bill 302, sponsored by Rep. Deborah Hudson, R-Fairthorne, would double the penalty for a first-time offense to \$100 and set the fine for each subsequent offense at \$200-\$300.

See FINES, Page 10A

Fines

Continued from Page 1A

The bipartisan measure also would put Department of Motor Vehicles points on licenses for those caught a second time, which could result in defensive driving courses being required or a suspended license. Points until now have been reserved for speeders, reckless driving and other serious moving violations.

The measure would have to be approved by both houses of the Legislature and Gov. Jack Markell. The General Assembly returned to Dover this week following spring recess, and both Democrats and Republicans have signed onto the legislation. Hudson on Monday said she came up with the bill because she too often sees younger drivers texting.

"I'm a grandmother now, and I have a whole different way of looking at things," she said. "This generation seems to be oblivious to some types of authority, and I think this will help."

Hudson said she toned the bill down slightly. Originally, she wanted to

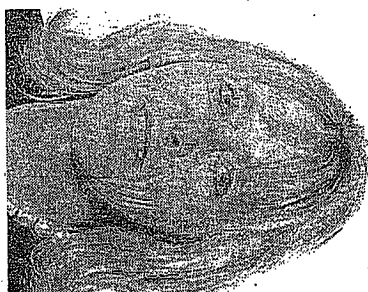
have points put on licenses for a first offense, but compromised after other lawmakers said they did not support that.

Those who earn enough points for traffic violations — like speeding, running a red light or reckless driving — face progressively more severe penalties.

Get eight points and you will receive an advisory letter; get 12 and you will have to complete a "behavior modification/attitudinal-driving course." Further offenses come with suspensions of a driver's license, up to a 12-month suspension for those who earn 22 points.

The legislation would toughen a ban passed in 2011, when Delaware became the 30th state to prohibit behind-the-wheel texting and eighth to bar the use of hand-held phones. AAA estimates more than 64,000 drivers have been issued citations since the law was passed, the two most-cited being age groups 20-24 and 25-29.

Sen. Karen Petersen, D-Stanton, who is the Senate sponsor of the new rules, said the additional fine is badly needed. She routinely sees drivers on their phones when she makes the trip down Del. 1



BOB HERBERT/THE NEWS JOURNAL
Rep. Deborah Hudson

to Legislative Hall, she said.

"If it were up to me, the police officer would take the phone, throw it on the ground and stomp on it with their foot," she said.

But motorist Kathy Fisher questioned whether the threat of additional fines will encourage drivers to drop the phone, which she says is a major problem on roadways.

"I just know that I see a lot of people texting and driving," said Fisher, of Newark, on Monday. "I don't know if doubling the fines is going to make them stop, but I guess I don't have a problem with it if it is a deterrent."

AAA Mid-Atlantic spokesman Jim Lardear said 18 states add points to licenses after a first of-

"This generation seems to be oblivious to some types of authority, and I think this will help."

REP. DEBORAH HUDSON, R-FAIRHORN

fense. The group supports the stricter penalties.

"I think most folks realize it's a risky thing to be doing," he said. "But we really fear that people don't take distracting driving seriously enough."

AAA Mid-Atlantic spokesman Jim Lardear said his organization supports increasing the penalties.

In a survey the AAA Foundation for Traffic Safety released this year, 2 in 3 drivers admitted to talking on a cell phone while driving, while 2 in 5 said they had read a text or email and 1 in 3 said they had typed or sent a message.

Between 2011 and 2014, 587 crashes involved cell phone use on Delaware roads, according to Office of Highway Safety reports

Distracted driving legislation

Delaware lawmakers are considering harsher rules on distracted driving. The measure would:

- » Toughens rules for those caught texting or using a handheld cellphone while driving
- » Doubles penalty for a first offense from \$50 to \$100.
- » Increases penalty for further offenses from \$100-\$200 to \$200-\$300.
- » Repeat offenders would get points on their license.

compiled by AAA.

"Distracted driving is one of our biggest concerns and one of our biggest focus areas," Lardear said. "You need good, strong laws; you need education about those laws and you need enforcement."

Lardear said studies show that peeking at a text or talking on the phone drastically reduces reaction times even after the driver puts down the phone. That can be deadly at highway speeds.

"People who think that they can drive and talk on the phone are mistaken," Lardear said. "Hands-free is not risk-free."

Forty-six states today forbid texting while driving, but only 14 states outlaw hand-held cellphone use like Delaware does, according to the National Transportation Safety Board.

An effective date has not been set yet for the

new rules. Motorist Bob Mina said the changes can't come soon enough.

"Anything that's going to get peoples' hands and eyes and brains on the road and off their phones, I'm all for," said Mina, who works in Christina. "There's enough distractions out there on the road without looking at your phone."

Petersen said lawmakers need to take the threat seriously.

"It's more dangerous than drunk driving," Petersen said. "I don't know what it's going to take to get them to get them to stop doing it. Increasing the fines is really the only tool we have."

Dannian Giletto of The News Journal contributed to this story.

Contact Matthew Albright at malbright@delawareonline.com, (302) 324-2428 or on Twitter @TNJ_malbright.



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The Dangers of Texting While Driving

The popularity of mobile devices has had some unintended and even dangerous consequences. We now know that mobile communications are linked to a significant increase in distracted driving, resulting in injury and loss of life.

- The National Highway Traffic Safety Administration reported that in 2012 **driver distraction was the cause of 18 percent of all fatal crashes – with 3,328 people killed – and crashes resulting in an injury – with 421,000 people wounded.**
- **Forty percent of all American teens say they have been in a car when the driver used a cell phone in a way that put people in danger**, according to a Pew survey.
- The Virginia Tech Transportation Institute found that **text messaging creates a crash risk 23 times worse than driving while not distracted.**
- **Eleven percent of drivers aged 18 to 20 who were involved in an automobile accident and survived admitted they were sending or receiving texts when they crashed.**

Distracted driving endangers life and property and the current levels of injury and loss are unacceptable.

To stem this problem, the FCC is working with industry, safety organizations, and other government agencies, to inform and educate the public about the dangers of distracted driving and is seeking to identify and facilitate the development of innovative technologies that could reduce the incidence of distracted driving. To help in this effort and share information, we created a [dedicated website \(/encyclopedia/distracted-driving\)](#).

Distracted Driving Information Clearinghouse

In addition, to collect and share information about consumer outreach activities and technology that could potentially reduce the problem of distracted driving, the Commission's staff created the [FCC Distracted Driving Information Clearinghouse \(/encyclopedia/distracted-driving-information-clearinghouse\)](#).

State Laws

Currently there is no national ban on texting or using a wireless phone while driving, but a number of states have passed laws banning texting or wireless phones or requiring hands-free use of wireless phones while driving. For more information on state laws, visit www.ghsa.org/html/stateinfo/laws/cellphone_laws.html (http://www.ghsa.org/html/stateinfo/laws/cellphone_laws.html).

What You Can Do

Give Clear Instructions – Give teen drivers simple, clear instructions not to use their wireless devices while driving. According to Cellular Telecommunications Industry Association, the easiest way to say it is: “On the road, off the phone.” Before new drivers get their licenses, discuss the fact that taking their eyes off the road – even for a few seconds – could cost someone injury or even death.

Lead by Example – Children learn from their parent’s behavior. No one should text and drive. Be an example for your children and if you need to text or talk on the phone, pull over to a safe place.

Become Informed and Be Active - Review the information in our Clearinghouse and the literature on the websites mentioned above. Set rules for yourself and your household regarding distracted driving. Tell family, friends and organizations to which you belong about the importance of driving without distractions. Take information to your children’s schools and ask that it be shared with students and parents.

For More Information

For more information about wireless devices and driving, visit the FCC’s Distracted Driving website at www.fcc.gov/encyclopedia/distracted-driving ([/encyclopedia/distracted-driving](http://www.fcc.gov/encyclopedia/distracted-driving)).

Consumer Help Center

For more information on other consumer issues, visit the FCC’s Consumer Help Center at <https://consumercomplaints.fcc.gov> (<https://consumercomplaints.fcc.gov>).

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[Texting While Driving Guide \(https://transition.fcc.gov/cgb/consumerfacts/drivingandtexting.pdf\)](https://transition.fcc.gov/cgb/consumerfacts/drivingandtexting.pdf) (pdf)

Date Last Updated/Reviewed:

Wednesday, November 4, 2015 - 2:30pm

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Simulator shows texting danger

MATTHEW ALBRIGHT

THE NEWS JOURNAL

With lawmakers set to approve stiffer penalties for those who text while driving, groups advocating against distracted driving brought a “virtual reality” simulator to Legislative Hall Tuesday. The simulator came to the state capitol building thanks to AAA and AT&T, which is in the midst of an “It Can Wait” campaign aimed at convincing drivers, particularly young people, to “keep their hands on the wheel and their eyes on the road.” The system uses a visor and headphones to immerse the viewer in the simulation, allowing them to look around in three dimensions. Several driving scenarios play that are interrupted with text messages, leading to near-misses and finally a huge crash. The groups usually deploy the simulator in schools — they were at A.I. du Pont High School on Monday — but several legislative staffers and even some state leaders got to take it for a spin on Tuesday.

“The sensation is such that you don’t ever want to text while driving again,” State Rep. Deborah Hudson, R-Fairthorne.

Hudson is sponsor of the bill that would double the fine for a first time offense of texting or using a handheld phone to \$100 and set the fine for each subsequent offense at \$200 to \$300. Repeat offenders would also see points added to their license.

Gov. Jack Markell stopped in to try the simulator, but he said he did not need any convincing.

“I don’t think people understand just how dangerous texting and driving is,” he said. “I don’t need any convincing.”

Contact Matthew Albright at malbright@delawareonline.com, (302) 324-2428, or on Twitter @TNJ_malbright.



STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
MARGARET M. O'NEILL BUILDING
410 FEDERAL STREET, SUITE 1
DOVER, DE 19901

VOICE: (302) 739-3620
TTY/TDD: (302) 739-3699
FAX: (302) 739-6704

MEMORANDUM

DATE: April 26, 2016

TO: All Members of the Delaware State Senate
and House of Representatives

FROM: Ms. Daniese McMullin-Powell, ^{D.M.-P/20} Chairperson
State Council for Persons with Disabilities

RE: H.B. 268 (Substance Exposed Infants & Medically Fragile Children]

The State Council for Persons with Disabilities (SCPD) has reviewed H.B. 268 which seeks to codify certain sections of the federal law known as the Child Abuse Prevention and Treatment Act ("CAPTA"). While the proposed legislation may be well-intentioned, it has drastic unintended consequences. Background is included in the attached articles. In a nutshell, approximately 3% of babies born in Delaware qualify for a diagnosis of neonatal abstinence syndrome (NAS) in which the infant undergoes opiate withdrawal. That percentage has been growing in recent years. DFS substantiates abuse in approximately 10% (44/448) of cases of suspected neglect or abuse reported to it among babies born with drugs or alcohol in their system. See attached March 7, 2016 News Journal article. Medical professionals prefer to place pregnant women with addictions on methadone resulting in only short-term effects on babies treated for withdrawal upon birth. See attached "Addicted babies", Delaware News Journal (November 20, 2015).

H.B. 268 (lines 63-64) would require health care providers to report substance exposed infants not more than 4 weeks of age (line 51) to the DSCY&F. Such reports would be entered into the child protection registry on the same basis as reports of abuse or neglect (lines 79-81). Although reports of abuse or neglect can be made anonymously, this is not permitted for reports of substance exposed infants (lines 82-84). A "plan of safe care" would be developed for cases accepted by DFS for investigation or family assessment (lines 16-19 and 110-111). Apart from substance exposed infants, the bill would also require development of a plan of care for cases accepted for investigation or family assessment involving any "medically fragile child" (lines 126-127) of any age (lines 42-44).

While the proposed legislation may be well-intentioned, it has drastic unintended consequences as currently written.

First, the legislation reinforces an autocratic model in which the State imposes requirements and offers little help to new mothers with substance abuse profiles. The bill (lines 45-50) contemplates unilateral development of the “plan of safe care” with zero input from the parent. This “top-down” plan is then shared with agencies but not the parent (lines 47-49). This kafkaesque approach is not a collaborative model which “engages” the new mother in a joint venture to benefit her infant.

Second, the articles describe successful outcomes for parents receiving wrap-around services while highlighting the paucity of resources available to many parents:

Holly Rybinski, of Newport, said she had to go to jail in order to get the drug treatment she needed. That was almost two years ago. She had stayed clean for five years, but while she was pregnant with his child, her partner overdosed and died. Consumed with grief, Rybinski turned to heroin and cocaine during the last five months of her pregnancy. After she gave birth to the son James April 8, 2014, at Christiana Care’s Wilmington Hospital, she was ready to be clean. She said the Division of Family Services told her that they had to take custody of him since James tested positive for drugs, she wasn’t in a treatment program and Rybinski had a record. They told her she had 90 days to find employment, treatment and stable housing and then they could discuss putting him back in her care. That request was easier said than done. ...”I tried five different times to get into treatment,” Rybinski said. “It was one obstacle after the other.” As the number of pregnant and addicted mothers grows, the need for treatment is even more critical. Community members, families and those now in recovery, like Rybinski, have long lamented Delaware’s lack of residential treatment options. Many people have to wait days and even weeks to get a bed. ...Currently, there is one state-run treatment program for expectant or new mothers recovering from addiction in Delaware, but it is only for women who are incarcerated and it is in Newark. ...Brandywine Counseling ran a program for expecting moms wrestling with addiction, called Lighthouse, downstate in Ellendale, but is closed in September due to budget cuts and staffing shortages. ...(It was extremely successful. Nearly 100 percent of women were able to give birth to babies free of drugs.

“More treatment key for addicted moms”, Delaware News Journal (March 4, 2016)

Third, the bill envisions development of the same autocratic “plan of safe care” for any parent of a “medically fragile child” of any age if the parent is “unable” to “provide or ensure necessary care” (lines 42-44 and 126-127). The definition of “medically fragile child” is extremely broad, i.e., essentially covering any child at risk of a condition that requires services of a type or amount beyond that of an average child (lines 42-44). The implication is that parents of a child with a disability are at fault, culpable if they cannot guarantee (“ensure”) necessary care, and subject to the same “plan of safety care” as parents delivering addicted babies. This is reminiscent of the

1960s view of autism as caused by “frigid” mothers - stereotyping parents of children with disabilities as ‘at fault’ for their child’s medical condition.

Fourth, the central plan of care for medically fragile infants and toddlers is the collaborative family support plan developed under Title 16 Del.C. §§214 and 215. It is counterproductive to supplant the family support plan with a “plan of safe care” administered by a child neglect/prevention agency.

SCPD has the following recommendations:

1. The “medically fragile child” references (lines 42-44 and 126-127) should be deleted.
2. The “plan of care” provisions (lines 45-50) should be amended as follows:
 - a. Ensure parental input and collaboration in development of the plan; and
 - b. Ensure that the plan includes support services rather than simply directives or benchmarks for parents to achieve on their own. For example, consider the following amendment:

The plan of care shall identify all material impediments to family preservation and the itemized, available resources specifically offered to the parent to overcome each impediment including, if relevant:

- a. mental health treatment;
- b. substance abuse treatment;
- c. safe housing; and
- d. any public assistance program operated or administered by a State agency.

3. The State should expand resources and programs available to expectant mothers with addictions and mothers of substance exposed infants.

Thank you for your consideration and please contact SCPD if you have any questions regarding our observations on the proposed legislation.

cc: The Honorable Matthew Denn
Mr. Brendan O’Neill, Public Defender’s Office
Ms. Teresa Avery, Autism Delaware
Mr. Brian Hartman, Esq.
Governor’s Advisory Council for Exceptional Citizens
Developmental Disabilities Council

HB 268 substance exposed infant & medically fragile children 4-19-16

Addicted babies

11-20-15
MS

CHAPTER 1

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Katie Morgan is a heroin addict in recovery, a 29-year-old expecting a child in January.

She is part of a novel Delaware corrections program; Rather than serving time in prison for drug crimes and probation violations, Morgan is being held at a Newark group home – where she receives treatment for addiction, and can retain custody of her baby.

Methadone, the synthetic opioid Morgan takes to treat her heroin addiction, courses through her blood and the blood of the baby boy she's carrying.

That means her newborn will likely spend his first weeks in the throes of opiate withdrawal – fighting neonatal abstinence syndrome, or NAS, a condition that makes babies sleep-deprived, irritable, prone to tremors and vomiting, and difficult to feed.

The first sensations felt by her child will be similar to what heroin addicts feel when they quit cold turkey – wracked with pain, clawed by cravings.

"I can imagine what he's going to go through when he comes out. I've been through withdrawal before," Morgan said, sniffing. "I'm really upset with myself. I cry about it a lot because I did it to him. But he's healthy, and the doctors say he's going to be OK. So, it's just a mistake I have to learn from."

Morgan's predicament is becoming far more common in America. Heroin use more than doubled in the last decade, and more and more babies are starting their lives in withdrawal. In 2004, 39 babies were discharged from a Delaware hospital after being treated for NAS. Last year, 300 babies received that diagnosis – nearly 3 out of every 100 born here.



Delaware's heroin babies: Starting life in withdrawal

While heroin and methadone are much less likely to affect a child later in life than other drugs expectant mothers are urged to avoid during pregnancy – such as alcohol, tobacco and cocaine – the quick rise in NAS cases in Delaware is an unsettling trend.

Photo: Jason Minto/The News Journal

Christiana Hospital, which has seen more than twice as many NAS babies since 2010, announced plans Thursday for a \$260 million overhaul of its women and children's services at its Stanton campus. That expansion will create eight new floors and provide more room for its neonatal intensive care unit and a new nursery just for high-risk infants, such as those exposed to opioid drugs during pregnancy.

To medical staff accustomed to giving care in stressful conditions, infants with NAS can seem to be in agony. And caring for them is agonizing.

"What's different about babies who are born to moms on opiates is it does cause fairly immediate withdrawal symptoms," said Dr. David Paul, chief of pediatrics at Christiana Care. "Immediate means babies can show symptoms of withdrawal in the first hours after birth."

Adds Nancy Forsyth, a neonatal nurse at Beebe Hospital in Lewes: "They may cry inconsolably. If you listen to their cry, it's the cry of a baby that is in pain. It's really distressing to see a baby going through this."

Like other states around America, Delaware is struggling through the heroin pandemic. Overdose deaths have nearly tripled in the past decade – from 63 in 2004 to 185 in 2014.

High school nurses are being trained to give emergency doses of opiate-blocking drugs to prevent fatal overdoses, and police officers and emergency medical technicians carry the drug Narcan to save the lives of those who have overdosed.

In New Castle County, heroin seizures climbed 400 percent between 2012 and 2013, and emergency rooms are being inundated with overdose victims.

The signs of stress are visible statewide.

"The addiction epidemic is straining our public system beyond its capacity, with many people turned away for services when they are ready for treatment," Gov. Jack Markell said in August.

Jim Martin, the leader of a Georgetown home for homeless men and a director of a Seaford addiction resource center, knows of parents in Seaford who routinely sweep heroin baggies off their sidewalks so their children don't find them.

Heroin "has just exploded in our communities. It's like a nuclear bomb went off and little heroin packets are going everywhere," Martin said. "The experience I'm having dealing with heroin is folks seem to have so much more relapse. The drug just pulls you back, even if you've had some clean time. It's just a terribly addictive drug."

Three years into treatment for heroin addiction, Courtney Murphy, 31, brought her baby girl, Sophia, into the world on Oct. 27. Murphy had taken methadone and the baby showed signs of NAS in the hours after her birth, but made it through the rough patch and was discharged without much fuss six days later.

"Her tremors did scare me a little bit. I'd never experienced that," Murphy said as she rocked Sophia, in her Nike booties and a pink-and-white outfit, to sleep in her New Castle apartment.

Murphy's sons, ages 2 and 6, watched cartoons in a bedroom while, nearby, her 11-year-old daughter fussed with her hair. The church where Murphy attends addiction group therapy each week is just a few minutes' walk down the street.

"It's an everyday struggle," she said of her recovery from addiction. She said it began at age 18 after a car crash when she was prescribed opiate painkillers. She's been clean three years now.

"It's made me become a better mom," Murphy said. "My daughter's 11 – she'll be 12 soon – and I was actively using when she was younger" – taking street drugs in the child's presence. "Now, I've been able to

be there a lot. Not just physically. Mentally. Knowing what's going on with my kids. I mean, it's a big difference.

"I am doing the right thing. It's not being embarrassed by my drug history. I'm proud of myself today, from where I came from," she said.



31 year-old Courtney Murphy rocks her 2-week-old daughter Sophia while talking to Daniel, her 6-year-old son. A younger son, 2-year-old Duke, and Sophia were both born while Murphy was using methadone to treat her addiction to heroin.

(Photo: JENNIFER CORBETT/THE NEWS JOURNAL)

Drugs and delivery

CHAPTER 2

More than it ever has, heroin is reshaping lives throughout the United States. In 2005, 380,000 people said they had used heroin in the past year, according to the National Institute on Drug Abuse. By 2012, 670,000 people were in that group.

As public policy measures deliberately made it harder for people to access and abuse prescription drugs, they often turned to heroin (<http://www.drugabuse.gov/about-nida/legislative-activities/testimony-to-congress/2015/americas-addiction-to-opioids-heroin-prescription-drug-abuse>), "which is cheaper and in some communities easier to obtain than prescription opioids," the NIDA says.

The rise in heroin use is happening even as use of most other illegal drugs is dropping, according to the institute's research. Fewer people use cocaine and hallucinogens now than they did 10 years ago. But heroin's popularity is soaring.

Delaware's heroin babies: Starting life in withdrawal

In interviews around the state, doctors and nurses who work in obstetrics departments say an increasing amount of their time is spent in the care of women who are actively using heroin and other opiate drugs or, more commonly, being treated for addiction with methadone. It is a clinical scenario that used to pop up on occasion, but is now a near-daily reality.

"This is constant. It's pretty much all the time. It's rare that I don't have a baby who's been exposed [to opiates] here," said Beebe's Forsyth. "We used to have a lot of moms coming in on oxycodone, street or otherwise, when they came in to deliver. Now, we're not seeing that. All we're seeing, pretty much, is the methadone. ... It's pretty much a constant. Ask anybody else at a birthing hospital and they'll say the same thing."

Nationwide, about 16 percent of pregnant teens and 7 percent of pregnant women ages 18 to 25 use illegal drugs when pregnant, according to a federal survey of recent data. Between 2000 and 2009, the number of mothers using opiates during pregnancy increased 500 percent, according to a 2012 report by the American Medical Association.

The obstetrics field has seen the effects of drug abuse on pregnant women before, when the drugs involved were different. Alcohol abuse during pregnancy can lead to fetal alcohol syndrome and can cause facial deformities and brain damage; cocaine use by the mother can cause premature birth.

But heroin, as well as methadone, can lead to neonatal complications all their own, said Paul, of Christiana. About 60 to 80 percent of babies born dependent on either heroin or methadone develop symptoms of NAS.

An infant with NAS can show symptoms like tremors, irritability, an unsettling high-pitched cry, seizures, poor feeding, sneezing a lot, vomiting, diarrhea and difficulty breathing. All of this is because after birth, "the infant then begins to withdraw from the narcotics previously received from the mother in utero," as a 2013 article in the International Journal of Childhood Education put it. If not treated, NAS can be fatal.

In 2010, Paul said, 100 infants were treated for NAS at Christiana. In 2014, 170 were diagnosed there, the hospital where more babies are delivered in Delaware than at any other hospital. Statewide, 300 babies delivered at Delaware hospitals were diagnosed with NAS in 2014, compared to 242 babies in 2013, according to data Paul presented to other physicians in April.

About 10,900 babies were born in Delaware in 2014, according to federal health data. That means 2.7 percent of babies born that year were treated for NAS. More than that were evaluated for it because their mothers were known to have methadone or opiates in their systems, but not diagnosed.



Dr. David Paul, chair of the pediatrics department at Christiana Care Health System, talks about the hospital's care for drug-dependent infants right after they're born.

(Photo: JENNIFER CORBETT/THE NEWS JOURNAL)

The increased incidence of NAS is an echo of overall heroin use in Delaware. Drug treatment programs funded by the Delaware Division of Substance Abuse and Mental Health admitted 1,263 patients in 2011 whose primary drug was heroin. In 2014, that number was up to 3,182 heroin-dependent people, and for the third year in a row, those programs treated more heroin addicts in Delaware than users of any other drug.

"I've had 22-year-olds sit in my triage chair and they're crying. They're devastated. They know their lives have changed. They've burned through all their support systems," said Kathy Keating, a forensic nurse examiner program coordinator at Nanticoke Memorial Hospital in Seaford, speaking to a community group in September about the heroin crisis. "But when people are honest with me about their drug history, I thank them. As long as you know what's in them it's much easier to treat them."

"I am hopeful that at some point it's going to peak," Paul said of the heroin epidemic. "If we learn lessons going back to crack cocaine in the 1980s, it seemed like that was never going to end, but it largely went away as a problem. So it's my hope as a clinician, and as a citizen of Delaware, that we're going to see this wane at some point."

Pills led to addictions

CHAPTER 3

For many, opiate drugs legally prescribed for pain following an injury become the gateway to heroin addiction. Brittany Yost, 23, of Seaford was a 16-year-old playing school sports when injuries aggravated by softball and martial arts led to physical therapy. A doctor wrote her a scrip for Tramadol, an opioid pain medication; when Tramadol's usefulness faded, she said, she was prescribed Percocet, another narcotic.

"Percosets became my new addiction and the way I coped with a lot of the pain," Yost said in an interview at New Expectations, a Department of Corrections-supported home for pregnant women who have been sentenced for criminal offenses and are also undergoing methadone treatment. "And I found myself, every single time I got depressed, using more and more all the time. Heroin was introduced by my brother."

Criminal offenses and probation violations, the first at age 17, led Yost to one of state's substance abuse programs for offenders, and then supervised probation. But while on probation, she used drugs again and her probation officer found out, landing her back behind bars this year.

"I was three weeks' pregnant when I went to jail. I didn't even know I was pregnant," Yost said. "Going through withdrawal, the risk of losing the baby and miscarriage and stuff, that definitely isn't an option for me."

Women in Delaware's correctional system can get methadone treatment while in prison only if they are pregnant, and Yost did so. But she said she knew other women in the prison considered her and other pregnant, methadone-using women beneath them, contemptible.

"There's a lot of other inmates who look down on you being in a pregnancy pod" and getting methadone treatments, Yost said. "It was depressing, in a way, but at the same time I knew it was the best option."

If she had not been caught using and learned of her pregnancy, Yost isn't sure she would have sought treatment for her addiction.

"Probably not, to be honest," she said quietly. The parole violation conviction, she said, "was sort of a blessing. The influences that were around me back then, they're not now, being that I'm in treatment."

To an outsider, it might seem surprising that medical professionals encourage expectant mothers addicted to opiates to use methadone instead of finding a way to completely flush opiates from their bodies by the time the baby is born.

But doctors and nurses interviewed for this story said outcomes are better for the baby if an expectant mother is following prescribed treatment for methadone, even though there is a decent chance the baby will develop NAS.

"The long-term outcomes seem to be a lot better for these babies than with fetal alcohol syndrome or your cocaine-addicted babies," said Dr. Erin Fletcher, a Lewes pediatrician who is on staff at Beebe Healthcare. "There are some studies showing possibly some higher ADHD or learning disabilities in the long term. But for the most part, it's not causing any major obvious birth defects. For the most part, once we get them through this treatment period, these babies tend to do very well."

For most people, going cold turkey is simply ineffective as a way of battling heroin addiction; the cravings for the drug are just too powerful. Methadone helps block the nervous system receptors in the brain that create the craving for the drug.

"Mothers in methadone programs are doing the best they can under unbelievably difficult circumstances," said Forsyth, the Beebe nurse practitioner. "That is a piece I always share with them. By seeking treatment and getting prenatal care, they have done the best thing they can for their unborn baby."



Brittny Yost poses for a portrait at New Expectations in Newark.
(Photo: KYLE GRANTHAM/THE NEWS JOURNAL)

Stigma an issue

CHAPTER 4

Underlying the concerns about NAS and newborn's health is a recognition that the infants' mothers, in most cases, are struggling, often in the middle of difficult recovery from addiction, and routinely stigmatized for being pregnant at the same time they're addicted to drugs.

"Having a child is difficult; babies are very demanding. When you add into that the stress of a parent who is, whether they are actively using or are in treatment, there's a tremendous burden of guilt," said Forsyth. "Dealing with those issues, as well as the guilt that they're feeling and a baby that is far more irritable and difficult to care for than most, is overwhelming."

Bridget Buckaloo, who directs women's health services at Beebe Healthcare, says medical staff should be careful not to stigmatize such women more than they already are.

"Nursing curricula, medical school curricula, dental school curricula: All these different aspects of health care really don't prepare us to deal with addiction. We don't have a good understanding of addiction as a disease," Buckaloo said. "We see it as a choice... A diabetic, we don't judge them for taking their insulin. People who have an addiction, who are substance dependent, they're at a point where they are taking the drug to feel OK. They're not taking the drug to get high. Most of these women have had some kind of trauma if you strip away the drug. The medication makes them feel better; it makes the pain of the trauma go away.

"As a health care profession, there's a lot of judgement and stigma we place on these mothers. It becomes a barrier to their recovery. It's sad, but it's true."

For pregnant women in the justice system, the New Expectations house can be a novel road to recovery. A joint project of the Department of Corrections and its contracted health care provider, Connections Community Support Programs, the Newark home blends in on a block sprinkled with college-student housing.

Delaware's heroin babies: Starting life in withdrawal

Women there are transported to prenatal care appointments; take part in group therapy and support counseling; and can see visitors once a week. If they complete their required probation term without breaking house rules, they can retain custody of their babies, which they couldn't do if they gave birth while incarcerated. The women can even stay at New Expectations for up to six months with their new babies, taking time to get on their feet.

Some of the women said they made the choice to seek treatment because of their pregnancies.

"When I found out I was pregnant, I was on the run for, like, 9 months," said Bonnie Quill, 32, of New Castle, in an interview at New Expectations. "I guess I was tired of running and I wanted to get it over with before the baby was born so I wouldn't have to be away from him."

As worried as the women in New Expectations are about methadone's possible effect on their babies, they are most concerned about the path their sober lives, out of the justice system, will take.

"They're trying to avoid incarceration, and they're trying to avoid having the baby taken away from them," said Catherine Devaney McKay, Connections' president and CEO. "Those are pretty serious first-order issues to address. The motivator is wanting to be out of jail when the baby is born, so you have a shot at keeping your baby."

Many women interviewed said they were determined not to return to the hometowns where they first became addicted, and where their circles of friends had, for years, included other addicts.

"Everybody that you seem to know is either doing pills or actually still on heroin," said Morgan, the Harrington woman due in January, recalling the times when she was at home in between probation violations. "They say change people, places, things. Even doing that, the new people that you meet seem to have a drug of choice, whether it be alcohol, marijuana or heroin. It seemed like somebody was always doing something."

The mothers have also given thought to how they will explain to their children, years down the road, what their lives were like when the children were born. Should they explain the whole scenario, drugs, addicts, handcuffs, courtrooms, tears and all?

"Without this program, I would be out there still," said Tamyra Broxton, a New Expectations client who was cuddling her two-month-old son, Makai Brown, born while Broxton was recovering from an addiction to PCP. "I'll tell him this was a time in my life I had to get myself together."

Carlos Duran, a neonatologist at Christiana Care, is the director of Child Development Watch in New Castle County, a public health effort that keeps tabs on children at risk for developmental delays. To persuade more mothers of babies who were drug-dependent at birth to take part in the program, he said, doctors linked up with Brandywine Counseling to see the mothers and their infants once a month at the same Brandywine facility they go to for rehabilitation and addiction treatment.

"The wave of new patients, that was really one of the main driving forces. We'd been seeing these babies before in our regular program, but it was a much smaller number," Duran said. "Within the last two years or so is when we have really seen the most need."

Doctors and social workers keeping tabs on NAS babies, he said, tend not to think the babies' development is held back by their brief opiate withdrawal window alone. If those children show developmental delays, he said, it's more likely because of other factors: unstable home lives, and parents still distracted by their own addiction problems.

"They don't have medical problems. Their needs are different. And we have a fairly high no-show rate for these families. They may not understand what we're doing, or they may not have transportation," Duran said. "We are working through the process of how much



Tamyra Braxton and her two-month-old son Makai Brown pose for a portrait at New Expectations in Newark.
(Photo: KYLE GRANTHAM/THE NEWS JOURNAL)

more we can really screen or ask. We don't want to be too intrusive, because this is a voluntary program. We don't want to be seen as Big Brother. We're still working on that: How much can we ask without driving them away?"

But, he said, even the parents struggling to raise their children want to do better.

"These moms, they love their babies and they want to do everything they can for them," Duran said. "We help the mom to better manage the baby."

For Murphy, the mother of two-week-old Sophia, her new normal is this: Her oldest daughter catches a bus to a charter school at 5:45 a.m. A 2-year-old son who was also born when she was taking methadone, Duke, walks to her father's house, where he'll be cared for. Murphy's husband, a painter, goes to his 12-hour shift at a Dover work site. Then, Murphy and Sophia make their way to the clinic where Murphy's methadone treatments are administered.

"I take the baby with me to the clinic. It's a job just to get there, back and forth every day," she said. When she can, Murphy makes time for Narcotics Anonymous meetings and church meetings on addiction. She's learned, in recovery, to plan a day ahead wherever she can — making lunches, laying out school clothes. It's a choreography she never could have sustained when she was abusing heroin.

In high school, "I was a cheerleader. I hated, despised anyone who did drugs. I never thought this would be my outcome," Murphy said as she got her children ready for a lunchtime walk to the corner deli. "But I'm making the best of the situation. So, that's all that matters."

Staff writer Jen Rini contributed to this story. Contact James Fisher at (302) 983-6772, on Twitter @JamesFisherTNJ or jfisher@delawareonline.com.



Courtney Murphy holds her 2-week-old daughter Sophia, who was born with symptoms of NAS, including tremors.
(Photo: JENNIFER CORBETT/THE NEWS JOURNAL)

Newborn addictions rise, triggering new hospital rules

 Jen Rini, The News Journal 1:14 a.m. EST January 18, 2016



(Photo: JENNIFER CORBETT/THE NEWS JOURNAL)

Following an increase in babies born with drug or alcohol dependencies in Delaware, statewide hospital discharge forms for "high-risk" cases will be amended to ensure that the baby will go home to the safest environment and mom will have the necessary support system in place.

A committee of medical professionals, community leaders and state officials charged with studying and recommending how to care for infants who are born substance-exposed or medically fragile voted to add six conditions that will automatically trigger high-risk medical discharge reports from the hospital to the Delaware Division of Family Services.

The move is one of the first steps the committee, an arm of the Child Protection Accountability Commission, has made to figure out how to best help babies born with the dependencies and their families thrive.

The conditions originally were crafted by the Delaware Healthy Mother and Infant Consortium, a group that reviews and recommends programs and guidelines concerning maternal and fetal care.

The conditions are:

- Significant noncompliance with care of the infant, such as not visiting or participating in care.
- Mom is using substances, but is not in a treatment program.
- Evidence that drug use impairs caregiving ability.
- Addicted infants must stay in the hospital for more than 30 days.
- Multiple substance use.
- Infant needs medically complex care.



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[Delaware's heroin babies: Starting life in withdrawal](#)

<http://www.delawareonline.com/story/news/local/2015/11/20/heroin-babies-starting-life-withdrawal/75208368/>

According to the form that is submitted to DFS, a high-risk medical discharge is called for if there is an "increased risk for physical, developmental, behavioral or emotional conditions that require health and related services of a type or amount beyond that required by a child generally, and the child's family is unable or unwilling to provide or ensure the necessary care."

If a pregnant woman heavily uses opiates, such as heroin, codeine, oxycodone and even methadone or buprenorphine – which are used in drug treatment, those substances filter through the placenta. The baby is then born drug-dependent and soon suffers withdrawal.

When an expecting mom drinks alcohol while the baby is developing in the womb, the baby can develop fetal alcohol syndrome disorders as well.

Jennifer Donahue, child abuse investigation coordinator of Delaware and co-chair of the committee, said it is important a plan of safe care is established for these children when they leave the hospital.

Hospitals are already required to report to Delaware Division of Family Services if a baby is diagnosed as being substance exposed or with a fetal alcohol spectrum disorder.

There were 448 reports made in 2015. Not all require follow-up, however, DFS investigated 299 cases of babies who tested positive for drugs and 68 who tested positive for alcohol.

But the follow-up for families can be inconsistent, Donahue said.



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[Hospitals adapt to handle more drug-addicted moms](#)

<http://www.delawareonline.com/story/news/2015/11/20/hospitals-adapt-more-drug-addicted-moms/76033968/>

State and community agencies are doing "damage control" now to try to connect families to services such as home visiting nurses and are tasked with investigating near-death, injury and death instances that involve drugs. For instance, such a child death could be the result of a mom on methadone rolling over onto a baby in bed, suffocating the infant.

Draft legislation is in the works to formalize a plan of safe care for babies that will engage social workers, nurses, hospitals and other groups to ensure that families will not fall through the cracks and the baby is not in danger. Mothers would need to sign off on the plan at the hospital and would be monitored to make sure they are following it appropriately.

"We are trying to make it clear and formal," Donahue said. "It's not a discharge plan; it's a follow-through plan."

Delaware newborn addictions rise, triggering new hospital rules

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without action, then we are going to have more babies, she said.

Others, such as Dr. David Paul, chair of the Delaware Healthy Mother and Infant Consortium and head of pediatrics at Christiana Care Health System, feel that the legislation is not the cure-all.

He is concerned that the legislation would actually deter moms from getting prenatal care or dissuade them from drug treatment. The legislation may be part of the solution, but it's not the only solution, Paul added.

"There's not going to be a silver bullet," Paul said.

Jen Rini can be reached at (302) 324-2386 or jrini@delawareonline.com. Follow @JenRini on Twitter.

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Editorial: To save the kids, treat the addicted parents

Editorial 6:01 p.m. EST March 4, 2016



(Photo: File)

At first glance, the deaths of kids like Aiden Hundley and Autumn Milligan ([/story/news/local/heroindelaware/2016/03/04/delaware-falling-heroin-babies/80930474/](#)) point to Delaware's failed effort to safeguard children born to drug-addicted parents.

But in the bigger picture, such deaths also intensify the spotlight on our state's need for more addiction treatment services.

A proposed measure called "Aiden's Law" would require addicted mothers to sign an agreement with the state that they will properly care for their addicted children – or risk losing custody.

While we support any effort to keep kids safe, it's critical to remember this: We can send all of the case workers in the world to check in on kids, but if their parents don't receive adequate treatment for their addictions, the child always will be in danger.

Just as children born with addictions need treatment, so do their parents.

As pointed out in the Sunday News Journal front-page story, more than 130,000 children born in the United States in the last decade entered the world hooked on drugs, according to a Reuters investigation.

Reuters identified 110 cases since 2010 in which babies and toddlers whose mothers used opioids during pregnancy later died preventable deaths.

In Delaware, four addicted babies died in the care of a parent or caregiver in 2015, and three others were severely abused.

To combat this tragic trend, it's critical that addicted mothers-to-be feel comfortable seeking and have easy access to the prenatal and addiction care they and their babies desperately need.

We know this can be done.

The News Journal highlighted [such an effort](#) ([/story/news/local/2015/11/20/heroin-babies-starting-life-withdrawal/75208368/](#)) in November. While it may not be practical or ideal to use several group home settings across the state, we believe further investment in and expansion of such a program will lead to far more positive outcomes.

And while it's a given that mothers and children are the first priority, addicted fathers need access to help, too. Addicts say that the already difficult task of getting clean is made all the tougher when they're around people who continue to use.

On top of that, access to effective services remains limited, though additional facilities are opening this year.

In 2015, there were 9,877 admissions into state-funded treatment facilities – the highest number in more than 10 years, according to data collected by the state health department. In 3,723 of those admissions, people identified heroin as their primary drug.

As we have [written in this space before](#) ([/story/opinion/editorials/2016/01/10/wrenching-film-shows-heroin-deadly-impact/78599492/](#)), opiate/opioid addiction is a scourge that does not discriminate.

There remains for some the belief that addicts can choose to get and stay clean – that opiate addiction itself is a choice.

Yet, while the decision to first use opiates rests with the user, the power of the subsequent addiction overwhelms all logic and reason.

Still, one would hope that the risk of losing custody of a child would be motivation enough for any addicted parent to accept help if offered.

That help may cost us more in the short term, but the long-term benefit of such an investment is seeing all of our children grow up to be healthy and productive members of society. As it stands now, too many kids die before they even know what the word "addiction" means.

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Hospitals adapt to handle more drug-addicted moms

James Fisher, The News Journal 7:39 p.m. EST November 21, 2015



(Photo: JENNIFER CORBETT/THE NEWS JOURNAL)

Hospital systems in Delaware are trying to adapt to a world in which heroin use and methadone treatment are increasingly marked "yes" on maternity ward intake forms.

At Christiana Hospital in Newark, those adaptations have included remodeling a section of the maternity unit into the Continuing Care Nursery, a place where NAS infants and their parents, as well as other babies who need special care, can stay several weeks after delivery. A \$500,000 contribution from the Junior Board of Christiana Care helped the nursery open.

"One of the major functions of that unit, and the reason we designed it, is to be able to handle a quieter environment," said Dr. David Paul, chair in Pediatrics at Christiana. Babies with NAS are more sensitive to light and sound than healthy infants; the constant beeping and foot-shuffling of a neonatal intensive care unit is actually a challenge to handle.

"Ultimately, they can go home faster if they stay out of the NICU," Paul said.

On Thursday, Christiana Care unveiled a \$260 million capital construction proposal that would turn the existing women and children's eight-story haven for expecting moms with more room for its neonatal intensive care unit and create single-family patient rooms.

If approved by a state board that guides hospital expansion efforts, the new building could be complete by 2020, hospital officials said.

To treat babies with NAS, doctors and nurses administer tiny doses of morphine (<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2708121/>) to relieve the pain of withdrawal from opiates, and within three to six weeks, also draw down the dose of morphine. The drug also helps with seizures, fever and weight loss.

"It's a substitution drug," said Fletcher, the Beebe pediatrician. "It occupies the same receptor sites and neurons in the brain so that withdrawal symptoms, minimizes cravings."

It may seem odd to give infants morphine, but it's a common treatment for NAS throughout the country. Still, doctors don't want to give newborns any more than they have to.

"There are emerging data that there's an association between length of medical treatment with morphine with adverse neurodevelopmental outcomes. The time we can keep babies on morphine in the hospital, potentially the better the baby's outcomes are," Paul said.

There are plenty of ways to soothe the babies that don't involve drugs, too. Tracey Bell, a NICU nurse educator at Christiana, said parents that "just holding them, cuddling them, giving them a quiet environment, talking to them softly and feeding them in a quiet area" can help. "They don't like a lot of additional stimulation," Bell said.

Volunteers assigned to the CCU will also cuddle and rock infants when parents aren't there. "That soothing, rhythmic rocking helps to settle any baby," said Pamela Jimenez, a nurse practitioner and coordinator of the CCU.



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Delaware's heroin babies: Starting life in withdrawal

<http://www.delawareonline.com/story/news/local/2015/11/20/heroin-babies-starting-life-withdrawal/75208368/>



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Raising awareness for fetal alcohol syndrome

<http://www.delawareonline.com/story/news/health/2015/11/20/raising-awareness-fetal-alcohol-syndrome/76056634/>

On average, Paul said, babies with NAS stay in the hospital for 15 to 18 days postpartum. In the NICU, there's no place for parents to sleep that many nights. But in the CCU, each room is private and has a pull-out sofa.

The medical community is coming up with ways to track the progress of these infants into their second and third years of childhood. At Christiana, Jimenez keeps tabs on the babies and their families by encouraging them to take part in Child Development Watch, a state-supported early intervention program. "It's making sure that mom's needs are being met, and making sure the baby is developing appropriately," Jimenez said.

Bridget Buckaloo, executive director of women's health services at Beebe Healthcare, said Beebe also follows state guidelines and facilitates referrals of all NAS babies for developmental screening.

Staff writer Jen Rini contributed to this story. Contact James Fisher at (302) 983-6772, on Twitter @JamesFisherTNJ or jfisher@delawareonline.com.

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More treatment key for addicted moms

Jen Rini and Estelna Perra, The News Journal 6 p.m. EST March 4, 2016



(Photo: JENNIFER CORBETT/THE NEWS JOURNAL)

Holly Rybinski, of Newport, said she had to go to jail in order to get the drug treatment she needed. That was almost two years ago.

She had stayed clean for five years, but while she was pregnant his child, her partner overdosed and died. Consumed by grief, Rybinski lured to heroin and cocaine during the last five months of her pregnancy.

After she gave birth to her son James April 8, 2014, at Christlana Care's Wilmington, he was born clean.

She said the Division of Family Services told her that they had to take custody of him because he was positive for drugs, she wasn't in a treatment program and Rybinski had a record. They told her she had 90 days to find employment and housing and then they could discuss putting him back in her care.

That request was easier said than done. There were issues with insurance coverage and doctors who would not approve her care because she had given birth only weeks before, she said.

"I tried five different times to get into treatment," Rybinski said. "It was just one obstacle after the other."

As the number of pregnant and addicted mothers grows, the need for treatment is even more critical. Community members, far from recovery, like Rybinski, have long lamented Delaware's lack of residential treatment options. Many people have to wait days at a bed. Many have to go out of state.

That was the case with Rybinski. She tried to get admitted to rehabs in Maryland and Pennsylvania before turning back to her home access.

The treatment options available do boast results.

Over the last three years, about 774 women were helped by a Brandywine Counseling program that helped connect women to training and case management. In that same period, 189 babies were born and 187 were born free of illicit drugs, data from the state. About 145 were delivered to full term and 133 were born within a healthy weight.



35 year-old Holly Rybinski, of Newport, plays 3 year-old daughter Scarlet after she got home from daycare. Rybinski just got out of prison over a week ago for burglary and possession charges that stemmed from her drug addiction. She is currently living with her parents during her recovery. (Photo: JENNIFER CORBETT/THE NEWS JOURNAL)



35 year-old Holly Rybinski, of Newport, plays with her 3 year-old daughter Scarlet after she got home from daycare. Rybinski just got out of prison over a week ago for burglary and possession charges that stemmed from her drug addiction. She is currently living with her parents during her recovery. (Photo: JENNIFER CORBETT/THE NEWS JOURNAL)

Currently, there is one state-run treatment program for expectant or new mothers recovering from addiction in Delaware, but it is only for women who are incarcerated and it is in Newark.

Run through the Delaware Department of Correction and Connections Community Support Programs, the DOC's healthcare provider, a judge can sentence women to the program, called New Expectations, as a condition of probation instead of house arrest or prison. The women live in a group home, receive prenatal care and take parenting classes.

Brandywine Counseling ran a program for expecting moms wrestling with addiction, called Lighthouse, downstate in Ellendale, but it closed in September due to budget cuts and staffing shortages.

About 28 to 40 women participated in the program at any one time over the five years it was active, said Lynn Fahey, Brandywine chief executive officer.

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Lighthouse wasn't just a group home – it offered a residential level of care to help women manage cravings with around the clock staffing. Fahey estimated it cost about \$700,000 a year to support, but data from Brandywine shows it was extremely successful. Nearly 100 percent of women were able to give birth to babies free of drugs, Fahey said.

In the year before it closed, about 98 percent of women enrolled in Lighthouse re-established relationships with their children or immediate family members. Nine cases investigated by DFS closed during the women's treatment and all women were able to find jobs.

"If the children had been taken, we were able to help the mom re-unify and get the children out of foster care," Fahey said. "It is an expensive level of care to do it right."

One of the other problems is spotty insurance coverage, explained MaryBeth Cichocki, a member of the advocacy group atTAack Addiction.

There is a set amount of time people can stay in residential treatment programs, typically up to 30 days, and then people are back out on the streets.

"Medical pays thousands and thousands and thousands of dollars for all these babies in the hospital," Cichocki said. "Yet if they would just get the mothers into a good rehab and keep them there until their brain starts to heal so the cravings aren't so powerful and the mom wants to use again."

Rybinski was one such mom that had difficulty getting treated.

Frustrated that she couldn't get care, she ramped up her drug use and started stealing from vehicles in New Castle County neighborhoods to feed her habit. Eventually she was arrested and sentenced to two treatment programs run through the DOC. DFS terminated her parental rights.

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35 year-old Holly Rybinski, of Newport, plays 3 year-old daughter Scarlet after she got home from daycare. Rybinski just got out of prison over a week ago for burglary and possession charges that stemmed from her drug addiction. She is currently living with her parents during her recovery. (Photo: JENNIFER CORBETT/THE NEWS JOURNAL)

Rybinski was just released after being incarcerated for 18 months. While she was in jail, a foster family brought James to see her every month. Her two other kids, Scarlet, now 3, and Gage, 8, stayed with her mom, and thought she was in "time out."

Had she been connected to treatment services immediately or had a halfway house to stay after she was discharged from the hospital, Rybinski said her life might have taken a different turn.

"I might have 18 months clean and been home for the past year," she said.

Though it wasn't a perfect scenario, she is grateful she was separated from James when he was born. She acknowledged that caring for a newborn and trying to manage her addiction could have been detrimental to his health.

"I don't think they should have given him back to me right then," she said.

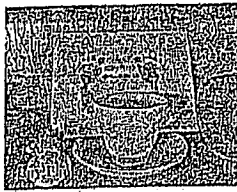
Now she's happy that she gets to see him every other weekend and he is going to be adopted by her partner's, his dad's, family. She's enjoying life with her other children, Scarlet and Gage, finishing her college degree in multimedia design, and counseling people struggling with addiction. Hearing Scarlet say "I love you to pancakes," the three year old's favorite food, is music to her ears.

"I let [addiction] become my life. I need to stay clean," she said. "I forgot what my purpose was."

Jen Rini can be reached at (302)324-2386 or jrini@delawareonline.com. Follow @JenRini on Twitter.

Delaware failing heroin babies

Esteban Parra and Jen Rini, The News Journal 11:38 a.m. EST March 7, 2016



(Photo: ESTEBAN PARRA/THE NEWS JOURNAL)

Delaware is failing babies born addicted to heroin and other drugs, the state Children's Department acknowledges.

Four addicted babies died in the care of a parent or caregiver in 2015, and three others were severely abused.

The September death of 8-month-old Aiden Ryder Hundley, who police say suffered horrible abuse at the hands of his parents, demonstrates gaping holes in the state's protocol for following up care of hundreds of addicted children annually discharged from Delaware hospitals to their parents.

A state commission and 16 state lawmakers are pushing legislation, named "Alden's Law," that would require mothers under investigation to sign an agreement with the state that they will properly care for their addicted children — or risk losing custody. It also would establish a unified plan all state agencies and community groups must follow in regard to at-risk children, eliminating the patch-work approach now being used statewide.

"We are going to have dead babies" without meaningful changes, Jennifer Donahue, statewide child abuse investigation coordinator for the Office of the Child Advocate, told a committee studying care for substance-exposed infants in January.

On Feb. 19 of last year, Aiden was born at Beebe Healthcare, one of several Delaware hospitals that tests all newborns for addictions. His first 27 days were spent in withdrawal, or neonatal abstinence syndrome, a condition ([/story/news/local/2015/11/20/heroin-babies-starting-life-withdrawal/75208368/](#)) that makes babies sleep-deprived, irritable, prone to tremors and vomiting, and difficult to feed.

After enduring that ordeal, the Division of Family Services permitted Aiden to be discharged into the custody of his parents, Doyle J. Hundley Jr., 37, and Casey R. Layton, 28, of Harbeson — both of whom have a long history of drug addiction, court records show.

The caseworker assigned to Aiden should have performed a thorough investigation on the parents and their wherewithal to provide a safe environment for the child, said Carla Benson-Green, cabinet secretary of the agency that oversees DFS. That didn't happen. And Hundley and Layton, like many addicts who frequently move from place to place seeking shelter from friends and family, were lost by DFS.



Carla L. Benson-Green, Secretary of the Department of Services for Children, Youth and Their Families talks about the children born with addictions. (Photo: JENNIFER CORBETT/THE NEWS JOURNAL)

Sixty-four days after the baby was discharged from the hospital, the caseworker found and visited the family but raised no red flags, Benson-Green said.

Two days later the parents called 911, explaining to first responders that the boy was having seizures. Doctors found freshly broken bones and bones beginning to heal from earlier breaks. He also suffered retinal hemorrhaging in both eyes, and he had an E. coli infection in his brain.

Aiden never left the hospital. He died Sept. 22 after being on life support four months.

The parents were charged with murder, contending the baby's injuries stemmed from abuse.

Hundley claims injuries to his son occurred when he tripped on a duffel bag while holding the baby.

The caseworker who failed baby Aiden will be held accountable, Benson-Green said. But rather than instituting sweeping reforms, she said she has made changes to get DFS employees to do a better job.

"If the process was followed, it would not have been neglect by the agency," said Benson-Green. "You've got to see the child. You've got to see the family. ... You have to assess the home. All of that did not happen in this

case."

Bringing agencies together

The Department of Services for Children, Youth and their Families has come under fire for other high-profile cases, such as the August 2014 death of Autumn Milligan ([/story/news/crime/2014/11/07/mom-charged-girls-death-investigated-four-times/18671593/](#)).

The 4-year-old girl was beaten to death by her mother in a seedy New Castle-area motel after being investigated four times for neglect by DFS. <http://www.delawareonline.com/story/news/local/heroinin Delaware/2016/03/04/delaware-failing-heroin-ba...> 3/11/2016

Delaware failing heroin babies

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A news Journal investigation detailed how DFS looked into four neglect complaints about her mother, Tanasia Milligan, including one brought by her sisters, who wanted the division to investigate the care of Autumn and her older brother, Ethan. That investigation was active at the time of the girl's death.



DELAWAREONLINE

To save the kids, treat the addicted parents

(<http://www.delawareonline.com/story/opinion/editorials/2016/03/04/save-kids-treat-addicted-parents/81335512/>)

Although the sisters told child protection officials that the kids' bodies had marks on them, authorities never examined Autumn or her brother Ethan for bruises.

Rather than forcing Milligan to better care for her children, state officials ruled that the complaint was unsubstantiated. DFS made the same ruling in three previous investigations, even though Milligan was living with a man alleged to be a pimp at a motel on U.S. 13, where Milligan sold her body and abused drugs.

Tiffany Greenfield, Milligan's older sister, said the state fumbled several chances to save a vulnerable child from her troubled mother. She would welcome a new law with teeth that holds parents accountable, but points out that her sister agreed to a DFS demand that she take better care of her children or potentially lose them. At the end of the day, Greenfield said, the state didn't enforce the agreement and the lack of followup resulted in Autumn's death.

"They made Tanasia sign an action plan," Greenfield said. "They told her she had to do this, and if she didn't, she was told this would happen. She (Milligan) did nothing that they had listed and nothing happened, except the death of my niece."

While these incidents are ultimately the parent's fault, Greenfield said, the state must step into the breach when children are at risk.

"I just hope they can get it together before another child loses their life," she said.

DFS admitted to flaws into the investigation of Milligan and acknowledged it was riddled with errors, confusion and systemic problems. In February 2015, the month Aiden was born, the state announced the results of an internal review and proposed several reforms aimed at averting a similar tragedy.

Four children have died since.

Jennifer R. Ranji, then-secretary of the Children's Department, said that in retrospect, it was clear they didn't do enough to protect Milligan's children. Last October, Ranji was appointed a judge on Delaware's Family Court by Gov. Jack Markell.

Benson-Green, who has worked in the department since its inception in 1982, took over in November. Even when caseworkers follow protocols, she said, there can be bad outcomes.

Sometimes the initial contact with a mother and baby occurs months after a referral is received. Other times, DFS gets wrong names or bad addresses or is hampered by a lack of communication between state agencies, including police and the Department of Justice.

"As of now there is no Delaware law that outlines what each agency has to do when there is a substance exposed infant," said Donahue, the investigator.

Federal law requires that a plan of safe care be established and that states have policy and procedures in place. While DFS has a protocol, other state agencies follow their own rules in regards to children at risk — meaning some newborns with drug dependencies won't be under the watchful eye of the state.

"We've seen because of that disparity, because of the different cases, there are breakdowns and some agencies do not know what their role is," Donahue said.



Jen Donahue, left, child abuse investigator for the state of Delaware, and Tania Culley from the Office of the Child Advocate go over statistics related to abuse and death in cases involving substance exposed infants Thursday at the Department of Services for Children, Youth and their Families. (Photo: DANIEL SATO/THE NEWS JOURNAL)

There were 448 cases of suspected neglect or abuse reported to DFS among babies born with drugs or alcohol in their system, and the agency reported it found enough evidence to investigate 296 of them. Those 296 cases involved 364 children. In 44 cases, abuse was substantiated, 11 more are still pending.

A DFS spokeswoman said that they do not keep more accurate statistics of the types or severity of neglect or abuse.

"This is our problem," said Tania Culley, child advocate for the state of Delaware, one of the leaders of the legislative effort. "This is Delaware's problem and we all need to hold hands together to help solve it and support these mothers while making sure these babies are safe."

Nationwide, more than 130,000 children born during the past decade entered the world hooked on drugs, according to a Reuters investigation. Reuters identified 110 cases since 2010 in which babies and toddlers — whose mothers used opioids during pregnancy — died unnecessary deaths.

Being born drug-dependent didn't kill these children. Each recovered enough to be discharged from hospitals, but they were sent home to families ill-equipped to care [\(/story/news/health/2016/01/17/newborn-addictions-rise-triggering-new-hospital-rules/78851632/\)](http://story/news/health/2016/01/17/newborn-addictions-rise-triggering-new-hospital-rules/78851632/) for them, the report found.

More than 40 of those children suffocated. Thirteen died after swallowing toxic doses of methadone, heroin, oxycodone or other opioids. In one case, a baby in Oklahoma died after her mother, high on methamphetamine and opioids, put the 10-day-old girl in a washing machine with a load of dirty laundry.

Linda Carpenter, a program director with the National Center on Substance Abuse and Child Welfare, is helping states avoid issues related to substance-exposed deaths among infants. Carpenter said she worked with Delaware officials on amending state code to align with federal law that requires a plan of safe care for moms and substance-exposed babies.

The legislation, co-sponsored by Reps Melanie George Smith, D-Bear, Ruth Briggs King, R-Georgetown, Senate President Pro Tem Patricia Blevins, D-Elsmere, Sen. Cathy Cloutier, R-Heatherbrooke, and 12 others would define what a plan of safe care means for babies and moms. It would require social workers, nurses, hospitals and other groups to make reports and share information to ensure that families can't move without notifying authorities, and that babies are not in danger.

To print the document, click the "Original Document" link to open the original PDF. At this time it is not possible to print the document with annotations.

"One of the concerns in Delaware is we send moms and babies home sometimes and then there's nobody monitoring or not monitoring on a regular basis and then something happens. And that shouldn't surprise anybody," Carpenter said. "The plan of safe care and timing is critical. That should be written and everyone is on board before the baby even leaves the hospital."

At a community meeting last fall, Briggs King heard cases where a substance-exposed child was sent home with a parent struggling with addiction and died, or nearly died. She wanted answers, but found they were hard to find -- even for a lawmaker.

"It just seems to be a big question mark there," Briggs King said. "We need to protect these children."

To draw attention to the lack of follow-up, she drafted a bill that would have allowed police or a physician to take temporary custody immediately if a child is born drug-dependent or suffering from fetal alcohol syndrome.

Briggs acknowledged that it could deter women from receiving the substance abuse treatment they need, so she dropped the legislation and instead is backing the other effort.

Helping moms get into a successful recovery program is one of the best ways to start her and baby on a good path, says Dr. Elizabeth Drew, medical director of Summit Behavioral Health in Pennsylvania.

But moms-to-be who are in recovery are often afraid to disclose their situation.

"We need to make women who are pregnant feel like they can come forward with an addiction without already feeling like they are going to lose custody of their child," Drew said.

'We've got to catch up'

Of the three deaths besides Aiden's last year, two involved instances in which a mother using methadone, a drug taken to kick a heroin habit, fell asleep and smothered her baby. The other baby died of Sudden Infant Death Syndrome.

Benson-Green said in these cases, her caseworkers did everything properly.

Delaware failing heroin babies

There have been many cases across the country where moms have had adverse reactions to methadone after giving birth, unintentionally harming their babies, Carpenter said. Studies have shown that methadone can increase the likelihood of SIDS.

After a mother gives birth her body changes, Carpenter explained, noting that the mom may not respond to methadone as she did before giving birth. If she is not being closely monitored and the dose is too high, she may feel sleepy or dizzy, which can affect how she cares for the baby.

There have been a number of cases in which moms on methadone have fallen asleep, inadvertently rolling onto the child and smothering it.



Doyle J. Hundley Jr., 37, and Casay R. Layton, 28, have been charged with the death of their 8-month-old son, Alden. (Photo: ESTEBAN PARRA/THE NEWS JOURNAL)

Benson-Green said caseworkers take it hard when a child dies because the state likes to believe it has everything in place to keep children safe. After Alden's death, DFS has changed its protocol. Now a supervisor must sign a hospital discharge letter acknowledging the caseworker's findings and clearing the newborn to be released to parents or caregivers.

There also is more training to help caseworkers recognize child abuse and its triggers, and a substance abuse counselor accompanies caseworkers to the hospital when parents test positive for drugs. An informal assessment is made about whether the parent needs additional services.

In spite of lapses that have resulted in the deaths of infants, Benson-Green said citizens should not give up on the state to care for children at risk.

"The vote of confidence should still be there from the public," Benson-Green said. "There should be no reason for them to waiver from it. It's a challenging job when you are always dealing with constant changes in family dynamics and family behavior and the fact that the culture within the community is changing."

"We've got to catch up and work with those things that are now set before us."

Sitting on the shelf of a messy home in Harbeson is a white ceramic tile, with "Alden Ryder" printed in black. A heart stands in for the the dot over the "i" in Alden, and tiny blue footprints decorate either side of Alden's date of birth and death – 02-19-15 to 09-22-15 (<http://story/news/crime/2015/12/11/mother-father-charged-killing-8-month-old-son/77143184/>).

A tea cup with a broken handle and the word "Mother" holds the tile upright. Those objects and the proposed law in the boy's name appear to be the only physical memories left of him.

Contact Esteban Parra at (302) 324-2299, eparra@delawareonline.com or Twitter @eparra3. Jen Rini can be reached at (302) 324-2386 or jrini@delawareonline.com. Follow @JenRini on Twitter.

Child Protection Accountability Commission findings

A review of findings reported last month to the Child Protection Accountability Commission, the committee writing the new legislation, cited instances of breakdowns:

- One child was not able to be seen by a local child abuse expert because of a dispute between the hospital and insurance company.
- A report was not made to the state Division of Family Services' when a victim's sibling was born substance-exposed in 2013.
- The same division did not verify a mother's participation with a substance abuse provider.
- There was a delay in planning for the safety of a dead baby's siblings residing in a home where the death occurred because the mother did not sign a safety agreement. The division also entered into a safety agreement via telephone with an out-of-state relative for the other children six days after incident.

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Over 600 babies in Delaware to be born addicted in 2016

Matthew Albright and Jen Rini, The News Journal 9:18 p.m. EDT April 28, 2016



(Photo: Jen Rini/The News Journal)

The number of babies born addicted to drugs or alcohol in Delaware will nearly double by the end of 2016, the secretary of the state's Childrens Department said Thursday, signaling an "alarming trend."

Secretary Carla Benson-Green announced the startling projection at a Dover press conference for Delaware's annual Kids Count report, where experts detailed how poverty, violence and chaotic households, many ravaged by addiction, influence a child's overall health.

"Children born and reared in healthy environments have a better chance of healthy outcomes at every stage of their lives," Benson-Green said.

Hospitals are required to report to the Delaware Division of Family Services if a baby is diagnosed as being substance-exposed or with a fetal alcohol spectrum disorder.

Benson-Green said the division received 353 reports of addicted newborns in 2015 and the number of new reports is estimated to reach over 600 by December. In 2012, 136 babies were born addicted.

Many factors contribute to those numbers, she said, and there needs to be a collaborative effort to treat the root causes of addiction to make meaningful change.

"The substance abuse itself is just horrific," she said.

STORY: [Legislature battles over poverty – but agreement possible \(/story/news/politics/2016/04/04/delaware-legislature-poverty/82417712/\)](#)

Dr. David Paul, Christiana Care Health System's chair of pediatrics, was a bit unsure of those predictions. Statistics from the state's Perinatal Cooperative showed that in 2013, 242 babies were born with neonatal abstinence syndrome, or addicted to opioids, and in 2014 and 2015, 300 and 314 were born respectively, which Paul said shows the numbers may be going down slightly.

Even so, Delaware still has to find a way to grapple with the prevalence of substance-exposed infants.

"It's certainly a big problem. It's a big societal problem," Paul said. "I think at the hospital level there has to be a call to action."

At Christiana Care, as of March 15, the hospital system had imposed a universal urine drug screen of moms when they go into labor, which based on national research, may be able to catch about 20 percent more cases of substance-exposed infants.

A continuing care nursery, specifically for infants with complex needs, like NAS, also has benefits. It houses about nine babies at one time, each in a private room large enough for a family to sleep overnight. By nature, the space is quieter and more intimate so moms can learn how to breastfeed or soothe a baby who is going through withdrawal. More one-on-one attention is available for the infants, too.

"It's a much more inviting space for the family to get involved in care," Paul said.

Preliminary research from the hospital, which will be presented at the Pediatric Academic Societies Meeting in Baltimore Saturday, shows that infants with NAS who receive care in the continuing care nursery decreased their hospital stay by 13 days, compared with NAS babies who stayed in the larger, more chaotic neonatal intensive care unit.

"It's having meaning in getting babies home sooner, exposing them to less medication and it's had a big impact," Paul said.

Outside of the hospital, another key to curbing the rise in addicted infants could be increasing opioid replacement therapies, such as methadone, for youth 18 and younger, says Cathy McKay, president, founder and CEO of Connections Community Support Programs.

"Those are the people that are about to become women of child-bearing age," McKay said. "If they enter their child-bearing years already addicted and we don't know about them they are going to be pretty far down the road when we get to them."

The state also needs to expand treatment and family therapy resources for women and children, she said, as well as increase access to long-acting birth control.

"The number-one way to prevent substance-exposed infants is to not have women get pregnant," McKay said.

The News Journal reported that when addicted infants leave the hospital they can face even more problems. Four addicted babies died in the care of a parent or caregiver in 2015, and three others were severely abused according to state data.

In general the number of calls to the state's abuse and neglect hotline is rising, Benson-Green said, reaching 19,000 in 2015 and on track to clear 20,000 by the end of this year.

Helping children who are victims of abuse or neglect is one of the most difficult jobs, Benson-Green said. The days are long, caseloads are high and interacting with hostile parents can be trying, she said.

Buy Photo



Carla L. Benson-Green, secretary of the Department of Services for Children, Youth and Their Families, discusses protocols of the agency and improvements that can be made for children of parents with drug addictions. (Photo: JENNIFER CORBETT/THE NEWS JOURNAL)

"Society has changed and people have become progressively more self-centered and more cruel than ever," she said.

Even though there is much work to be done in improving the health of Delaware's children, the Kids Count annual report featured some nuggets of progress. Fewer children are being born underweight or dying as infants. More kids' families have health insurance and fewer teens are having kids.

But child poverty is getting worse, with 20 percent of Delaware kids living in poor households. Social, economic and environmental factors all influence the health of a child, said Janice Barlow, director of Kids Count.

Poor children have a higher likelihood of developing chronic illness such as diabetes and have a greater chance of dying in infancy.

STORY: [Calls grow for fundamental change to school funding \(/story/news/2015/12/04/school-funding-povert/76728852/\)](/story/news/2015/12/04/school-funding-povert/76728852/)

STORY: [For city schools, a call for reinforcements \(/story/news/education/2015/03/06/city-schools-call-reinforcements/24534629/\)](/story/news/education/2015/03/06/city-schools-call-reinforcements/24534629/)

"A person's health is related to much more than whether or not they have insurance," Barlow said.

Many state leaders have said they want to make fighting poverty, particularly among children, a top priority. Several bills in the current legislative session, sponsored by both Republicans and Democrats, seek to tackle the problem.

Rising child poverty has also complicated attempts to improve Delaware's school system, particularly in places like inner-city Wilmington and Dover or rural Sussex County.

Educators have said growing homelessness, hunger and other poverty-related problems are placing obstacles in the way of learning.


A fierce debate over poverty in schools led to the creation of the Wilmington Education Improvement Commission, which has proposed a sweeping plan to redistrict city schools and rework Delaware's school funding formula so that high-poverty schools receive more money.

Over 600 babies in Delaware to be born addicted in 2016


The commission's plan was approved by the State Board of Education after several furious rounds of negotiations, and is one of the looming issues legislators hope to address before the General Assembly adjourns at the end of June.

Jen Rini can be reached at (302) 324-2386 or jrini@delawareonline.com. Follow @JenRini on Twitter. Contact reporter Matthew Albright at malbright@delawareonline.com, (302) 324-2428 or on Twitter @TNJ_malbright.

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Prevention and Behavioral Health Services

Division of Prevention and Behavioral Health Services

Susan A. Cycyk, M.Ed., CRC, Director
Julie Leusner, Psy.D., Deputy Director

Phone: 302-633-2600
e-FAX: 302-622-4475

Who we are?

The Division of Prevention and Behavioral Health Services (DPBHS) is part of the Delaware Department of Services for Children, Youth and Their Families. On July 1, 2010, the Division of Child Mental Health and the Office of Prevention and Early Intervention blended to become the new Division. DPBHS provides a statewide continuum of prevention services, early intervention services, and mental health and substance abuse (behavioral health) treatment programs for children and youth. These services have graduated levels of intensity and restrictiveness that are child-centered and family focused.

DPBHS' prevention and early intervention services focus on promoting safe and healthy children, nurturing families and strong communities through community and school-based initiatives. DPBHS' treatment services are accredited under the Business and Services Management Standards of the Commission on Accreditation of Rehabilitation Facilities (CARF) (<http://www.carf.org/>). In addition, the contracted and/or state operated treatment providers within the DPBHS network are licensed where appropriate and most are accredited under one of the nationally recognized accrediting agencies such as CARF (<http://www.carf.org/>), JCAHO (<http://www.jointcommission.org/>), COA (<http://www.coanet.org/>) or CHAP (<http://www.chapinc.org/>).

Mission

To develop and support a family-driven, youth-guided, trauma-informed prevention and behavioral health system of care.

Vision

Resilient Children and Families Living in Supportive Communities

DPBHS Strategic Plan

Strategic planning is a process of defining our direction, and making decisions on how to best pursue this strategy. Strategy generally involves setting goals and establishing smaller steps (objectives) that will lead to achieving the goals.

The DPBHS Strategic Plan (</pdfs/pbh-StrategicPlanCY13-16-update-2016.01.05.pdf>) was developed by the Division's leadership team.

Division of Prevention and Behavioral Health (/pbhs)
Families (/pbhs/pbhs_families.shtml)
Providers (/pbhs/pbhs_providers.shtml)
Advocacy (/pbhs/pbhs_advocacy.shtml)
Kids Line Newsletters (/pbhs/pbhs_newsletter.shtml)


"...By definition, a real plan is never final; it is a living document. As we move forward to accomplish our goals, we will learn new information that may be incorporated into our process and change how we move forward."

Susan Cycyk, Director

Questions regarding the strategic planning process should be addressed to Steve Perales at: Stephen.perales@state.de.us (mailto:Stephen.perales@state.de.us).

Questions regarding specific goals, objectives, etc. should be addressed to the person identified as the lead within the plan.

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 Who we serve?

The Division provides voluntary behavioral health services to children up to the age of 18 and their families who:

- Could benefit from programming and services that promote health and well-being
- Do not have insurance to cover behavioral health services
- Have Medicaid and who require more than the basic Medicaid 30-hour annual outpatient benefit available through the [Diamond State Health Care Plan](http://www.dmap.state.de.us/home/index.html).
(<http://www.dmap.state.de.us/home/index.html>)

[DPBHS Eligibility Policy \(/policies/pbh/cs001-Service-Eligibility-2015.pdf\)](/policies/pbh/cs001-Service-Eligibility-2015.pdf)

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 How to obtain services

 Organizational Structure

 Commitment to Quality

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Department of Services for Children, Youth and their Families (/index.shtml)

Crisis Services (/services/crisis.shtml) | Child Abuse (/fs/fs_iseethesigns.shtml) |

Prevention (/fs/fs_prevent.shtml) | Sitemap (/sitemap.shtml)

Share (<http://www.addthis.com/bookmark.php?v=250&pub=stateofdelaware>)

Delaware.gov (<http://www.delaware.gov>) | Privacy

(<http://www.delaware.gov/help/privacy.shtml>) | Translate

(<http://www.delaware.gov/help/translate.shtml>) | Contact

(http://smu.portal.delaware.gov/cgi-bin/mail.php?contact_us) | Phone Directory

(<http://www.delaware.gov/phonedirectory/>)



Division of Prevention and Behavioral Health Services
 Department of Services for Children Youth and Their Families
 State of Delaware

CS 001	DPBHS SERVICE ELIGIBILITY		
Authored by:	DPBHS Leadership Team	Title:	
Approved by:	Susan Ccyk, M.Ed., C.R.C.	Title: Division Director	
Signature:	<i>Susan A Ccyk 4/5/16</i>	Revisions: 12/19/99; 11/19/03; 8/31/05; 11/29/06; 11/1/07; 12/17/08; 8/10/10, 7/11/11; 4/18/12; 4/15/13, 4/17/14; 9/8/15	Originated: 5/1/97

PURPOSE: To define eligibility criteria for services provided by the Division of Prevention and Behavioral Health Services ("DPBHS"), State of Delaware.

DEFINITIONS: Applicable definitions are given in the appendix to DPBHS policy "Development and Revision of Policies."

POLICY: Consistent with statutory authority (16 Del C. chapter 90), agreement with the State Medicaid Office under the Medicaid waiver, DPBHS hereby establishes eligibility criteria for mental health and substance abuse services for children and youth who are served by DPBHS. Eligibility for service is established when criteria 1., 2., 3., and 4. below are all met or when criteria 5. is met.

1. Age: Children and youth are eligible:
 - A. Up to Age 18 - Children and youth are eligible for services until their 18th birthday.
 - B. Over age 18 - For those youth active with DFS or DYRS and over the age of 18 and less than 19 years of age, DPBHS may provide consultation, monitoring, and or diagnostic services.

2. Residence: Delaware residents are eligible for services.
3. Medical Necessity: Medical necessity is established by the application of DPBHS "Level of Care Criteria." These criteria are available on the DPBHS website.

4. Categorical Eligibility:
 - A. Insurance and Medicaid Benefits: DPBHS services are intended as a primary resource for those who have
 - 1) Medicaid benefits, and who require more than the basic Medicaid 30-hour annual outpatient benefit; or
 - 2) Uninsured, or
 - 3) Exhausted all applicable private insurance mental health or substance abuse benefits. The absence of a specific level of care or specific provider in a mental health insurance package is not sufficient grounds for categorical eligibility.

 - B. Co-Insurance: DPBHS does not function as a secondary payor for the purpose of funding insurance co-payment or deductibles for the privately insured. There are two exceptions:
 - 1) If a youth is hospitalized in a DPBHS designated psychiatric hospital on an involuntary basis, or is hospitalized on an emergency basis with DPBHS authorization, and the hospital is unsuccessful in obtaining reimbursement for the private insurance, then DPBHS may reimburse the Provider up to the allowable Contract rate for up to 72 hours.
 - 2) If a youth has both private insurance and Medicaid, the private insurer is the primary payor and Medicaid is the secondary payor. However if the youth is treated by a participating Medicaid provider, then the parent, legal guardian or other legally liable individual is not responsible for any copay amount and, by federal regulation, private providers may not bill parents for that amount. In such a situation, Medicaid providers who have a contract with DPBHS may be reimbursed up to the Medicaid rate in cases pre-authorized by DPBHS. If the provider and Medicaid recipient wish to utilize any applicable Medicaid coverage to pay costs after the primary insurance has paid allowable

charges, the provider must obtain DPBHS authorization upon exhaustion of private insurance for the service, in addition to any other authorizations which may be required by other payors.

C. DPBHS does not provide services that substitute for services which are the responsibility of another agency. However, for clients meeting eligibility requirements for DPBHS services, and who also qualify for services from other state agencies, divisions within state agencies, school districts, physical/medical health care services, and/or other services, DPBHS will provide medically necessary mental health and substance abuse services arranged in concert with other involved agencies. For example, when eligibility criteria are met and the child has a moderate to severe mental health disorder that is not explained by an underlying developmental disorder, PBHS may authorize or co-fund medically necessary care in concert with the education system and/or the Division of Developmental Disabilities Services. Also, DPBHS may provide or co-fund mental health and substance abuse treatment for children and youth active with another DSCYF division when the child meets PBHS eligibility criteria.

5. Mental Health Crises – Crisis services may be provided to children and youth meeting criteria A. or B. below.

A. DPBHS crisis services and short-term emergency hospitalizations may be provided to non-resident youth under the age of 18 years of age who are in the State of Delaware and are at imminent danger to self or others arising from mental health or substance abuse disorders. DPBHS reserves the right to seek reimbursement for services provided to non-Delaware residents.

B. The DPBHS crisis service also may be utilized by privately insured persons if they meet criteria 1., 2., and 3. above for initial crisis response (excluding crisis bed) intervention, but subsequent treatment is the responsibility of the insurance carrier unless the youth otherwise meets eligibility criteria and is admitted to DPBHS services.

APPLICATION:

A. The application of this policy in a particular circumstance may be appealed by the affected parent or guardian, custodian or other legal caregiver if the parent is unavailable. (See also DPBHS Appeals Policy).

1) Providers and advocates may assist children and families with an appeal under this policy.

2) Families will be advised of their appeal rights whenever a client is determined to be ineligible for DPBHS services under this policy.

When DFS or DYRS has legal custody, staff in disagreement with DPBHS decisions should use the DSCYF case dispute resolution procedures instead of the appeal procedures.

B. DPBHS staff may request a review by the Division Director if application of the policy would yield a result substantially contrary to the combined interests of the State and the client. The decision of the Director will be documented in writing and signed by the Director, and kept on file by the DPBHS Quality Improvement unit.

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I. Clinical Eligibility Determination

The Division of Substance Abuse and Mental Health (DSAMH) LTC system serves adults (age 18 years and older) with severe and persistent behavioral health disorders who meet disability, duration of illness and diagnostic criteria. The LTC System provides services for: individuals enrolled in Medicaid; individuals with dual eligibility of Medicaid and Medicare; individuals with Medicare only coverage; individuals without insurance coverage; and those with limited insurance coverage.

Clinical eligibility for and enrollment into the DSAMH Long Term Care (LTC) system will be determined by the DSAMH Eligibility and Enrollment Unit (EEU). The EEU will process all applications for enrollment into the DSAMH LTC System.

Clinical Eligibility Criteria for Enrollment into the DSAMH LTC System

- are age 18 years and older; and
- are U.S. citizens or have a legal resident alien status; and
- are residents of the State of Delaware; and
- are determined to have a specific primary DSM-IV diagnosis as listed below (Eligible Mental Illness Diagnoses and Eligible Substance Abuse Diagnoses) that has resulted in functional impairment which substantially interferes with or limits one or more major life activities [as determined by a formal DSAMH EEU review of the clinical information submitted in a complete [Enrollment Application Form](#)]; and
- present a history of having received intensive behavioral health treatment in one or more community or institutional programs including: Delaware Psychiatric Center; DSAMH Continuous Treatment Team programs; group homes, and long-term residential substance abuse treatment facilities; and/or
- present a history of having had multiple alcohol and other drug detoxification admissions and/or multiple intensive substance abuse treatment episodes.

Special eligibility determinations will be made for adults with developmental disabilities/mental retardation who have a severe and persistent behavioral health disorder and are in the upper mild range of mental retardation (317.0).

All individuals meeting the clinical eligibility criteria will be enrolled in the DSAMH LTC system.

Eligible Mental Illness Diagnoses

Schizophrenia and Other Psychotic Disorders

Code	Diagnosis
295.10	Disorganized Type
295.20	Catatonic Type
295.30	Paranoid Type
295.40	Schizophreniform Disorder
295.60	Residual Type
295.70	Schizoaffective Disorder
295.90	Undifferentiated Type
297.10	Delusional Disorder

Mood Disorders

Major Depressive Disorder, Recurrent

Code	Diagnosis
-------------	------------------

296.30	Unspecified
296.32	Moderate
296.33	Severe Without Psychotic Features
296.34	Severe With Psychotic Features

Bipolar Disorders

Code	Diagnosis
296.40	Bipolar I Disorder, Most Recent Episode Hypomanic
296.50	Bipolar I Disorder, Most Recent Episode Manic
296.60	Bipolar I Disorder, Most Recent Episode Mixed, Unspecified
296.70	Bipolar I Disorder, Most Recent Episode Unspecified
296.80	Bipolar Disorder NOS
296.89	Bipolar Disorder II

Personality Disorders

Code	Diagnosis
301.00	Paranoid Personality Disorder
301.22	Schizotypal Personality Disorder
301.83	Borderline Personality Disorder

Eligible Substance Dependence Diagnosis**Substance Dependence Diagnosis**

Code	Diagnosis
303.90	Alcohol Dependence
304.00	Opioid Dependence
304.10	Sedative, Hypnotic or Anxiolytic Dependence
304.20	Cocaine Dependence
304.80	Polysubstance Dependence
304.90	Other (or unknown) Substance Dependence; Phencyclidine Dependence

Clinical Eligibility Exclusions

DSAMH LTC services will not be available for:

- Adults with DSM-IV diagnoses not listed as eligible. Adults with the following DSM-IV developmental disabilities/mental retardation diagnoses: 318.0 (Moderate Mental Retardation); 318.1 (Severe Mental Retardation); 318.2 (Profound Mental Retardation); and 319.0 (Mental Retardation, Severity Unspecified); and
- Adults with DSM-IV diagnoses not listed as eligible.

Requests for a clinical eligibility determination should be submitted on a consumer's/client's behalf by any Managed Care Organization (MCO) participating in the Diamond State Health Plan (DSHP) or by a behavioral health provider currently treating the consumer/client. The referral process will remain the same for all organizations submitting a request for a clinical eligibility determination and enrollment. The documentation for a clinical eligibility determination is independent from the financial eligibility determination for Medicaid, Medicare and other third party insurance liability. Financial eligibility determination for Medicaid will be performed by the DHSS/Division of Social Services (DSS).

The requesting MCO or behavioral health organization must provide full documentation regarding medical necessity when applying for a consumer's/client's clinical eligibility determination for and enrollment in the DSAMH LTC system. This will include full documentation regarding the consumer's/client's utilization of behavioral health services prior to the request for clinical eligibility determination.

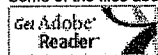
The requesting organization must complete the Enrollment Application Form and submit it to the Director of the EEU. The requesting organization will ensure that all information needed to make a timely decision for a clinical eligibility determination will be provided to the EEU. In addition to submitting the Enrollment Application Form, the requesting organization must designate a Clinical Liaison to serve as a point of contact regarding issues of referral.

The EEU will review the referral packet for completeness and quality. Incomplete packets will be returned to the referring organization for completion within one (1) working day of DSAMH's receipt of the incomplete application.

Upon receipt of a complete referral packet, the EEU will evaluate the clinical documentation provided, complete an **Eligibility Determination Review** and make a determination as to the consumer's/client's eligibility for the DSAMH LTC system within one (1) working days of receipt of the complete application.

The EEU will provide written notification to the referring organization and the consumer/client of the results of its eligibility determination within one (1) working days of the review's completion. Notification to the referring organization will include a copy of the **Eligibility Determination Summary**.

Some of the files above are in Adobe Acrobat format. You can view them with Adobe Acrobat Reader. For your free copy please visit [Acrobat](#)



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1115 Demonstration Amendment for State of Delaware PROMISE (Promoting Optimal Mental Health for Individuals through Supports and Empowerment) Program Changes

August 22, 2014

Introduction

The State of Delaware (State) is seeking an amendment to their existing 1115 demonstration waiver to comprehensively meet the needs of individuals with behavioral health (BH) needs, including individuals identified under the State's Olmstead settlement with the United States Department of Justice. The 1115 demonstration amendment is being submitted following submission of a State Plan Amendment (SPA) for crisis intervention, substance use disorder (SUD) treatment, and treatment by other licensed practitioners.

The PROMISE program seeks authority to target individuals with behavioral health needs and functional limitations in a manner similar to an Home and Community-Based Services (HCBS) 1915(i) State Plan authority. The HCBS authority under an 1115 amendment is sought, instead of a 1915(i) State Plan Amendment, to ensure coordination with the Diamond State Health Plan (DSHP) Plus program, to allow the State to include State Plan BH services in the managed care organization (MCO) benefit package, and to allow the State to competitively procure vendors under its new HCBS BH program, identified as PROMISE (*Promoting Optimal Mental Health for Individuals through Supports and Empowerment*). The demonstration amendment ensures that the freedom of choice waiver required for the procurement under this new HCBS program is granted under the State's current 1115 demonstration waiver and includes all affected individuals' costs under a single Centers for Medicare and Medicaid Services (CMS) authority. In particular, because of the small size of the State and low volume of services needed, the State will be competitively procuring contractors under the demonstration to meet the high quality and fidelity standards required under the Olmstead ADA settlement.

- For adult Medicaid populations meeting targeting and functional limitations statewide, the State will offer an enhanced benefit package of HCBS using HCBS authority in the 1115 demonstration. Generally, this includes individuals meeting the Olmstead settlement BH target population as well as other Medicaid-eligible adults with serious mental illness and/or substance use disorder needs requiring HCBS to live and work in the most integrated setting. These services are provided in addition to the State Plan services to help maintain individuals in home and community-based settings. The enhanced Medicaid benefit package will be coordinated by the Division of Substance Abuse and Mental Health (DSAMH) through the fee-for-service (FFS) program in compliance with home and community-based standards and assurances and the signed Olmstead agreement. *This population will continue to receive non-BH and most non-enhanced BH Medicaid State Plan services through the MCO benefit. See the benefit sections below for a description of the covered services.* The State is also considering including non-medical transportation services in the State's existing transportation broker contract and this amendment would provide the freedom of choice authority necessary for that contract amendment.
- For adults served in MCOs throughout the State who are not in the PROMISE target populations, the MCOs will integrate all covered services for mental illness, SUDs, and physical health (PH) conditions under this demonstration.

The goals of the two delivery system models are to improve clinical and recovery outcomes for individuals with BH needs and reduce the growth in costs through a reduction in unnecessary

institutional care through care coordination, including initiatives to increase network capacity to deliver community-based recovery-oriented services and supports. This structure will also ensure care continuity for individuals depending on their levels of need.

Background

Many individuals who are not currently eligible for Medicaid receive critical BH services through State-only funds, federal block grant dollars, or other resources. Although the State already has expanded Medicaid eligibility, many of the individuals served in the BH system who have not historically been eligible for Medicaid become eligible for Medicaid under health care reform in 2014. Under this proposed demonstration amendment, the State plans to develop access to additional supports and services to better meet the BH needs of the Medicaid expansion population in 2014 and to better serve the target populations under the Olmstead settlement. These efforts are aimed at modernizing and improving the delivery of mental health and substance use services in Delaware to better meet the needs of those currently eligible, but also to build the foundation to ensure that there is a robust continuum of supports and evidenced-based options available in the future. It is the State's intention to offer the expansion population the same benefit package as the rest of Medicaid with any necessary wraps to ensure essential health benefits.

The management of severe and persistent mental illness (SPMI) and chronic and disabling SUD require specialized expertise, tools, and protocols which are not consistently found within most medical plans. As a result, for adult populations meeting the SPMI and SUD targeting and functional criteria statewide, specialty BH care within the State will be care managed by DSAMH on a FFS basis with MCO care managers participating in person-centered planning with DSAMH and the participants to fully integrate PH needs with BH needs.

The demonstration amendment seeks to address the issues arising from special needs populations with SPMI and/or SUD through a comprehensive, interconnected approach to providing services to all individuals with BH needs in Delaware, ensuring that the individuals served are receiving the most appropriate services to meet their needs in the most integrated settings possible.

PROMISE Program

In order to better treat individuals meeting SPMI and SUD targeting and functional needs criteria, Delaware will be providing an enhanced benefit package of HCBS services to adults (ages 18 and older) meeting the targeting and functional needs criteria for SPMI and SUD under the PROMISE program. All individuals who meet the targeting and functional needs criteria will receive specialized care management and care coordination consistent with established protocols for managing care for adults with SPMI and/or SUD. This includes providing for behavioral supports in community-based settings (individuals' own homes), as well as residential, employment, and day settings to help individuals live in the most integrated setting possible. DSAMH, through its network of care managers and providers, will ensure that all HCBS requirements and assurances are met. This initiative is intended to fundamentally meet the requirements of the Olmstead agreement signed with the United States Department of Justice, and to build a sustainable behavioral health system for Delaware.

PROMISE Eligibility Requirements

Demonstration enrollees applying for services must be screened by DSAMH using a standardized clinical and functional assessment developed for Delaware and based on national standards.

Individuals in PROMISE will not be eligible for the State's new Pathways 1915(i) State Plan Amendment Program because the PROMISE program is a more comprehensive program that includes all Pathways services as well as other services necessary for individuals with behavioral health needs to be supported in their homes. The Delaware-specific American Society for Addiction Medicine (ASAM) tool integrates the assessment and evaluation of both mental health and SUD conditions into a single document with an algorithm that can be used to determine functional eligibility and is designed to ensure appropriate treatment of individuals based on their medical and functional needs. State Medicaid eligibility staff will review financial criteria to ensure that applicants meet the community financial eligibility criteria. Individuals eligible for and enrolled in PROMISE may also be enrolled in the PLUS program if meeting the criteria for both programs unless the PROMISE individual has been identified as a CRISP individual under the ADA settlement. If the individual is identified as a CRISP individual, the individual will be enrolled in the PROMISE program only and will receive all services necessary for community living from the PROMISE program through CRISP. The CRISP program will not provide any services under the acute care MCO benefit. The PROMISE program will ensure that Medicaid payments are backed out of any state-only capitated payments made for the CRISP program thus ensuring no duplicate payment between CRISP/PROMISE and Plus. For individuals in PROMISE and PLUS, medically necessary PROMISE services will be provided in addition to any services that the individual is otherwise eligible for in PLUS if the individual is assessed as needing additional services and the services are outlined on the individuals Recovery Plan. The PROMISE care manager will coordinate with the Plus case manager, who will lead the individual's care team. To be eligible under the PROMISE HCBS program, individuals must meet one of the targeting criteria and the corresponding functional criteria under the Delaware-specific tool. The following are acceptable combinations for individuals eligible under the demonstration:

- Target criteria A and functional criteria A or C.
- Target criteria B and functional criteria B or C.

Targeting Criteria

Target Criteria A: An individual must have formally received one of the included Diagnostic and Statistical Manual of Mental Disorders (DSM) diagnoses that constitute the targeted portion of the State's definition of SPMI, or a diagnosis of post-traumatic stress disorder (PTSD) by a qualified clinician. Diagnoses include the following:

DSAMH Current SPMI Diagnosis Codes (updated 7/1/2012)			
DSM IV Code	DSM 5 Code	Disorder	DSM IV Category
295.10	295.90	Schizophrenia, Disorganized Type (<i>In DSM 5 Disorganized subtype no longer used</i>)	Psychotic Disorders ¹
295.20	295.90	Schizophrenia, Catatonic Type (<i>In DSM 5 Catatonic subtype no longer used</i>)	Psychotic Disorders
295.30	295.90	Schizophrenia, Paranoid Type (<i>In DSM 5 Paranoid subtype no longer used</i>)	Psychotic Disorders
295.40	295.40	Schizophreniform Disorder	Psychotic Disorders
295.60	295.90	Schizophrenia, Residual Type (<i>In DSM 5 Residual subtype no longer used</i>)	Psychotic Disorders
295.70	295.70	Schizoaffective Disorder	Psychotic Disorders

¹ In DSM 5, the associated diagnostic category is labeled, "Schizophrenia Spectrum and Other Psychotic Disorders".

DSAMH Current SPMI Diagnosis Codes (updated 7/1/2012)			
DSM IV Code	DSM 5 Code	Disorder	DSM IV Category
295.90	295.90	Schizophrenia, Undifferentiated Type (<i>In DSM 5 Undifferentiated subtype no longer used</i>)	Psychotic Disorders
296.30	296.30	Major Depressive Disorder, Recurrent, Unspecified	Mood Disorders ²
296.32	296.32	Major Depressive Disorder, Recurrent, Moderate	Mood Disorders
296.33	296.33	Major Depressive Disorder, Recurrent, Severe Without Psychotic Features (<i>In DSM 5, "Without Psychotic Features" is not a further specifier</i>)	Mood Disorders
296.34	296.34	Major Depressive Disorder, Recurrent, Severe With Psychotic Features (<i>In DSM 5, "With psychotic features" is its own specifier, and, when present, is used instead of Mild, Moderate, or Severe, not in addition to Severe</i>) ³	Mood Disorders
296.40	296.40	Bipolar I Disorder, Most Recent Episode Hypomanic ⁴	Mood Disorders
296.42	296.42	Bipolar I Disorder, Most Recent Episode Manic, Moderate	Mood Disorders
296.43	296.43	Bipolar I Disorder, Most Recent Episode Manic, Severe Without Psychotic Features (<i>In DSM 5, "Without Psychotic Features" is not a further specifier</i>)	Mood Disorders
296.44	296.44	Bipolar I Disorder, Most Recent Episode Manic, Severe With Psychotic Features (<i>In DSM 5, "With psychotic features" is its own specifier, and, when present, is used instead of Mild, Moderate, or Severe, not in addition to Severe</i>) ⁵	Mood Disorders
296.50	296.50	Bipolar I Disorder, Most Recent Episode Depressed, Unspecified	Mood Disorders
296.52	296.52	Bipolar I Disorder, Most Recent Episode Depressed, Moderate	Mood Disorders
296.53	296.53	Bipolar I Disorder, Most Recent Episode Depressed, Severe w/o Psychotic Features (<i>In DSM 5, "Without Psychotic Features" is not a further specified</i>)	Mood Disorders
296.54	296.54	Bipolar I Disorder, Most Recent Episode Depressed, Severe w/ Psychotic Features (<i>In DSM 5, "With psychotic features" is its own specifier, and, when present, is used instead of Mild, Moderate, or Severe, not in addition to Severe</i>) ⁶	Mood Disorders
296.60		Bipolar I Disorder, Most Recent Episode Mixed, Unspecified (<i>This Bipolar 1 sub-type was removed from DSM 5</i>)	Mood Disorders
296.62		Bipolar I Disorder, Most Recent Episode Mixed, Moderate (<i>This Bipolar 1 sub-type was removed from DSM 5</i>)	Mood Disorders
296.63		Bipolar I Disorder, Most Recent Episode Mixed, Severe Without Psychotic Features (<i>This Bipolar 1 sub-type was removed from DSM 5</i>)	Mood Disorders

² In DSM 5, mood disorders are broken out into "Depressive Disorders" and "Bipolar and Related Disorders".

³ The DSM 5 code for Major Depressive Disorder, Recurrent, with Psychotic Features is 296.34.

⁴ In DSM 5 code 296.40 is also used for "Bipolar I Disorder, Current or Most Recent Episode Manic, Unspecified".

⁵ The DSM 5 code for "Bipolar I Disorder, Current or Most Recent Episode Manic, with Psychotic Features" is 296.44.

⁶ The DSM 5 code for "Bipolar I Disorder, Current or Most Recent Episode Depressed, with Psychotic Features" is 296.54.

DSAMH Current SPMI Diagnosis Codes (updated 7/1/2012)			
DSM IV Code	DSM 5 Code	Disorder	DSM IV Category
296.64		Bipolar I Disorder, Most Recent Episode Mixed, Severe With Psychotic Features (<i>This Bipolar 1 sub-type was removed from DSM 5</i>)	Mood Disorders
296.70	296.70	Bipolar Disorder, Most Recent Episode Unspecified	Mood Disorders
296.89	296.89	Bipolar II Disorder	Mood Disorders
297.1	297.1	Delusional Disorder	Psychotic Disorders
301.0	301.0	Paranoid Personality Disorder	Personality Disorders
301.20	301.20	Schizoid Personality Disorder	Personality Disorders
301.22	301.22	Schizotypal Personality Disorder	Personality Disorders
301.83	301.83	Borderline Personality Disorder	Personality Disorders
309.81	309.81	Posttraumatic Stress Disorder (PTSD)	Anxiety Disorders ⁷

Target Criteria B: Individuals may also meet other targeted DSM diagnoses. The DSM diagnosis must be among those that are included in the following larger DSM categories (excluding pervasive developmental disorders):

- Mood Disorders:
 - *In DSM 5 "Depressive Disorders" and "Bipolar and Related Disorders" are separated out as diagnostic groupings.*
- Anxiety Disorders:
 - *DSM 5 includes a separate category, "Obsessive-Compulsive and Related Disorders".*
 - *DSM 5 includes a separate category, "Trauma- and Stressor-Related Disorders".*
- Schizophrenia and Other Psychotic Disorders:
 - *In DSM 5 this category is labeled, "Schizophrenia Spectrum and Other Psychotic Disorders".*
- Dissociative Disorders
- Personality Disorders
- Substance-Related Disorders:
 - *In DSM 5 this category is labeled, "Substance-Related and Addictive Disorders".*

Functioning Criteria

Each person who is screened and thought to be eligible for PROMISE must receive the State-required diagnostic and functional assessment using the Delaware-specific ASAM tool.

⁷In DSM 5, PTSD is moved to another diagnostic category, called "Trauma- and Stressor-Related Disorders".

Functional Criteria A: If the individual meets Targeting Criteria A, the individual must be assessed with a rating of moderate on at least one of the six Delaware-specific ASAM dimensions. The six dimensions include the following⁸:

1. Acute intoxication and/or withdrawal potential — substance use.
2. Biomedical conditions/complications.
3. Emotional/behavioral/cognitive conditions or complications (with five sub-dimensions, including suicidality, self-control/impulsivity, dangerousness, self-care, and psychiatric/emotional health).
4. Readiness to change (with two sub-dimensions, including understanding of illness and recovery, and desire to change).
5. Relapse, continued use, continued problem potential.
6. Recovery environment (with two sub-dimensions, including recovery environment and interpersonal/social functioning).

Functional Criteria B: If the individual does not meet Targeting Criteria A, but does meet Targeting Criteria B, the individual must be assessed with a rating of severe on at least one of the above six Delaware-specific ASAM dimensions.

Functional Criteria C: An adult who has previously met the above targeting and functional criteria and needs subsequent medical necessary services for stabilization and maintenance. The individual continues to need at least one HCBS service for stabilization and maintenance (i.e., at least one PROMISE service described below in Table 3).

PROMISE Benefits and Cost-Sharing

Effective with MCO re-procurement, adults under PROMISE will receive through MCOs all non-BH Medicaid State Plan services, as well as the following State Plan non-enhanced BH services:

- Hospital (inpatient general hospitals including BH stays in psychiatric units⁹; emergency room (ER); outpatient; inpatient psychiatric care the age 21¹⁰).
- Physician — all types except for psychiatric providers employed by and providing supervision to the PROMISE program services of assertive community treatment (ACT), intensive case management (ICM), and residential supports.
- Pharmacy — all excluding medication assisted treatment.
- Crisis intervention.

The following BH State Plan services will be provided FFS with care coordination through DSAMH for adults receiving services under PROMISE:

- SUD services including medication assisted treatment.
- Services by licensed BH practitioners.

⁸ 2nd edition ASAM by Dr. David Mee-Lee et al. at <http://www.asam.org/publications/patient-placement-criteria/ppc-2r>.

⁹ 42 CFR 440.10.

¹⁰ 42 CFR 440.160. Note: because this program is for individuals ages 18 and over, this reference to adults in inpatient psychiatric care under age 21 refers to individuals ages 18-21 as indicated under the approved Delaware State Plan.

Division of Prevention and Behavioral Health Services (DPBHS)
Strategic Plan for Calendar Year 13-16

Goals	Objectives	How to measure	Lead	Status
<p>Goal Three: Enhance access to services through multiple pathways</p>	<p>3.1 Work on transition services and service coordination for transition to age 21</p>	<ul style="list-style-type: none"> Work with DHSS & other partners towards policy and budget development 	<p>Webb</p>	<ul style="list-style-type: none"> PBH is participating on a youth transition workgroup led by Judge Nicholas in Kent County. Project CORE was awarded to PBHS. This is a SAMHSA grant, in concert with DSAMH, to prevent psychosis in youth and young adults and to assist with the transition from youth BH services to the adult BH system. Susan Cycyk has met with Jane Gallivan, Director, Division of Developmental Disabilities Services on multiple occasions to discuss deeper collaboration with DDS. Follow up meeting set for January 2016. Project CORE was awarded to PBHS. This is a SAMHSA grant allows that provides resources for PBHS, in concert with DSAMH, to implement the PIER Model
	<p>3.2 Work on services and service coordination for children and youth who have developmental disabilities in addition to mental health/substance abuse disorders</p>	<ul style="list-style-type: none"> Work with DDS and other partners towards policy and budget development Seek opportunities to implement the PIER Model in collaboration with DSAMH 	<p>Leadership Team</p>	<ul style="list-style-type: none"> Reclassification completed. Re-bid for contracted psychiatric services successfully completed Revised rates for psychiatric services are in place. Contracts were finalized with 4 providers to participate in the Primary Care Physician-Psychiatrist Consultation Project pilot program: Two Psychiatrists, one Primary Care site in Kent County, and one primary care site in Sussex County. Following initial implementation of services, La Red has elected to discontinue participating. Telepsychiatry is available at Stevenson House, People's Place in Milford and at the La Red locations in Seaford and Georgetown.
	<p>3.3 Increase access to Psychiatric and Advance Practice Nurse Care</p> <ul style="list-style-type: none"> Recruit child psychiatrists willing to consult with Primary Care Physicians Investigate Tele-Health Participate in Statewide access efforts Assure capacity for medication evaluation and management services 	<ul style="list-style-type: none"> Reclassify Division child psychiatry position to a level that offers increased wages (Refers to state employment positions) Re-bid PBH contracted psychiatric services Develop a budget projection based on regional fair market value for psychiatric services. Tele-Health implemented 	<p>Margolis</p>	<ul style="list-style-type: none"> Reclassification completed. Re-bid for contracted psychiatric services successfully completed Revised rates for psychiatric services are in place. Contracts were finalized with 4 providers to participate in the Primary Care Physician-Psychiatrist Consultation Project pilot program: Two Psychiatrists, one Primary Care site in Kent County, and one primary care site in Sussex County. Following initial implementation of services, La Red has elected to discontinue participating. Telepsychiatry is available at Stevenson House, People's Place in Milford and at the La Red locations in Seaford and Georgetown.

Division of Prevention and Behavioral Health Services (DPBHS)
Strategic Plan for Calendar Year 13-16

<p>3.6 Prevention as access (if needed) to more intense treatment</p> <ul style="list-style-type: none"> Well informed providers and Partners who know how to access services. 	<ul style="list-style-type: none"> Implement Block Grant recommendations Train Prevention providers and partners in obtaining outpatient services for their participants (Track the training) Track source of referrals for outpatient 	<p>Warner</p>	<ul style="list-style-type: none"> Guide to Prevention Services disseminated to all staff, including presentation at PBH Managers meeting, division-wide email distribution and posting full document on PBH Extranet Working to implement quarterly Prevention provider training to increase knowledge of available treatment services and how to access FCTs and BHCs have been trained and updated on current prevention services and referral process.
<p>3.7 Review Crisis System</p> <ul style="list-style-type: none"> As recommended via system review 	<ul style="list-style-type: none"> Review completed and accepted by Leadership Recommendations on process Consider opportunities to work more closely with DSAMH's adult mobile crisis and address transitional age students 	<p>Perales/ Doppelt</p>	<ul style="list-style-type: none"> The Child Priority Response Review Committee convened from April 2013 through June 30, 2013. Several stakeholders including Acute Care Team, DGS, DFS, family members, Education and the Courts participated in the discussions. On June 29, 2013, the committee delivered its recommendations. Received permission from SAMHSA to use part of our SOC grant to fund an expansion of our Crisis Services. RFP for Crisis Services expected in FY '17.
<p>3.8 Increase Assessments within natural environment and enhance family engagement</p>	<ul style="list-style-type: none"> Increase numbers of assessments completed Track and report on timeliness Track and report on family engagement, satisfaction, practical applicability of assessments 	<p>Giddens/ Leusner Doppelt</p>	<ul style="list-style-type: none"> Currently tracking assessment numbers, timeliness and satisfaction surveys. CAS is meeting demand with reduced staff. Meeting court requirements.

EXCERPT
EIGHTH REPORT OF THE COURT MONITOR
ON PROGRESS TOWARD COMPLIANCE
WITH THE AGREEMENT:
U.S. v. STATE OF DELAWARE

U.S. District Court for the District of Delaware, Civil Action No: 11-591-LPS

12/26/2015

130 As is presented in Figure-4, RRC has demonstrated impressively high rates of diverting
131 individuals from hospitalization, including those being evaluated under 24-hour detention orders.
132 As has been discussed in previous Monitor reports, the State is developing a new Crisis Walk-In
133 Center, patterned after the RRC and its “living room” model, to serve New Castle County. That
134 facility is currently under construction. Once it is operational, EEU will direct individuals under
135 24-Hour Detention orders to that facility as it currently does in the State’s southern counties.
136 Until the new facility opens (likely early in 2016), CAPES—the Crisis Walk-In Center located in
137 a general hospital—continues to provide services to the northern part of the state, including 24-
138 Hour Detention evaluations for some individuals and a significant number of individuals
139 continue to be evaluated at an IMD.

140 The State is in Substantial Compliance with the Agreement’s requirements with respect
141 to Crisis Walk-In Centers.

142

143 D. Crisis Stabilization Services

144 *Partial Compliance.*

145 Section III.D.3 and III.D.4 of the Agreement delineate requirements for the State to
146 reduce its acute inpatient bed days in the IMDs and in DPC¹¹ by 30% and 50%, respectively,
147 relative to the base year of 2011. Prior reports of the Monitor have included extensive
148 discussions of these provisions and the State’s difficulties in meeting these targets. To briefly
149 summarize the issue, the State’s arrangements for oversight of acute psychiatric hospital care for
150 people with SPMI had been quite complicated, with accountability dispersed among DSAMH,
151 DMMA, and the MCOs operating under contract with DMMA. The entity or entities responsible
152 for monitoring the quality and appropriateness of an individual’s hospital care could shift, based
153 upon limitations in Medicaid coverage or referral for more intensive specialized services
154 including those required by the Agreement. Furthermore, the responsibility for ensuring that
155 individuals were appropriately referred for such critically needed intensive services was vague,
156 at best.

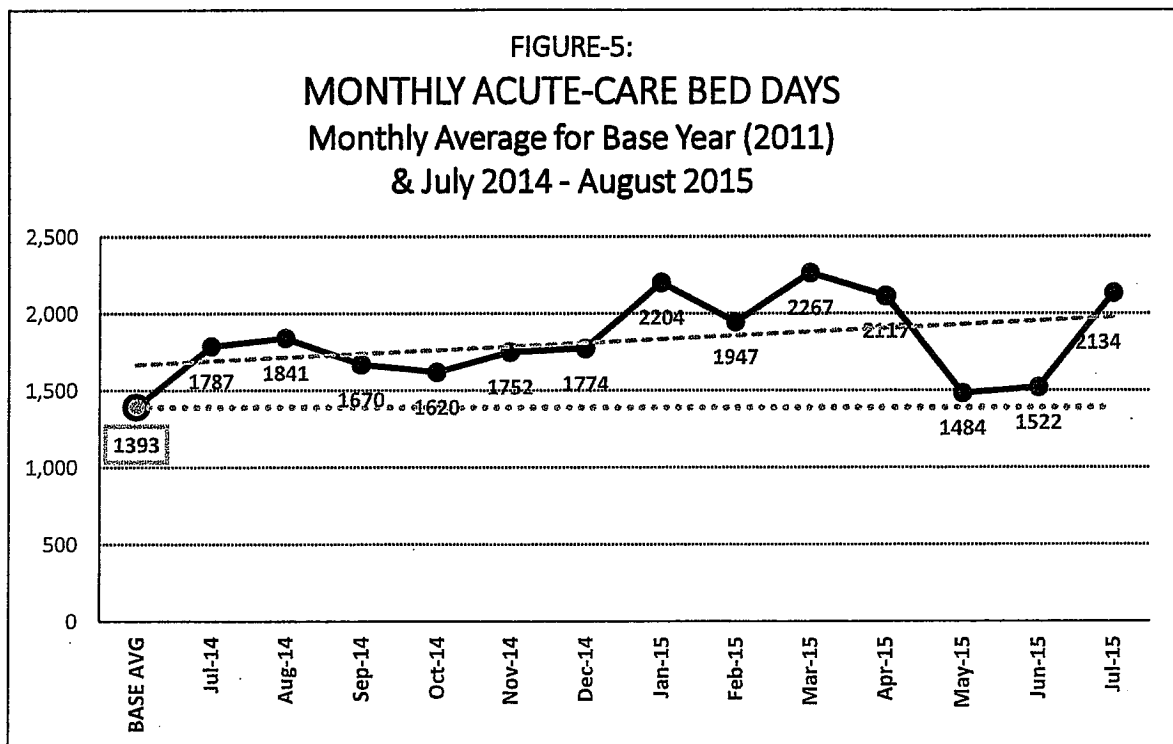
157 Inpatient psychiatric care is sometimes warranted, but it is also intrusive, it can be
158 coercive or traumatic, and it is an expensive service that drains resources that could be used
159 otherwise. The Agreement anticipates that the array of community program alternatives required
160 in its provisions, once fully operational, will significantly reduce the State’s reliance upon
161 hospital care by the percentages referenced above. As such, the number of inpatient days used by
162 the target population reflects the culmination of these new programs. For all of these reasons, the
163 Crisis Stabilization provisions of the Agreement are particularly important in demonstrating the
164 State’s alignment with the requirements of the ADA and *Olmstead*, around which it was
165 substantially crafted.

¹¹ Delaware Psychiatric Center (DPC) is the state-operated psychiatric hospital located in New Castle, Delaware.

166 Data presented in prior reports of the Monitor showed that the State has been successful
 167 in reducing inpatient days dedicated to long-term care at DPC,¹² but the State was not only
 168 failing to decrease the acute inpatient days referenced in Section III.D, these bed-days were
 169 increasing.

170 Figure-5 presents the State's monthly totals for acute-care psychiatric hospital bed days
 171 used by the target population.¹³ The monthly average number of acute-care bed days in the base
 172 year (2011) preceding the agreement was 1,393 (indicated by a dotted line). As is indicated in
 173 this chart, acute-care bed days for each of the months since July 2014—including the months
 174 since PROMISE was implemented in January 2015—have exceeded this level, sometimes
 175 significantly. Likewise, the trend line (the dashed line in the chart) shows a general upward
 176 trajectory with respect to acute care bed-day use.

177



178

179 The increases in acute care bed-days are essentially attributable to hospital stays at the
 180 IMDs. 87% of the bed-days categorized by the State as acute care occurred in the IMDs¹⁴ and

¹² Provisions in Section III.D relating to bed day reductions refer to acute care bed use only. The Agreement does not include specific numerical targets for long-term psychiatric hospitalization, but it does incorporate provisions to reduce unwarranted long-term care (e.g., Section IV.A-B).

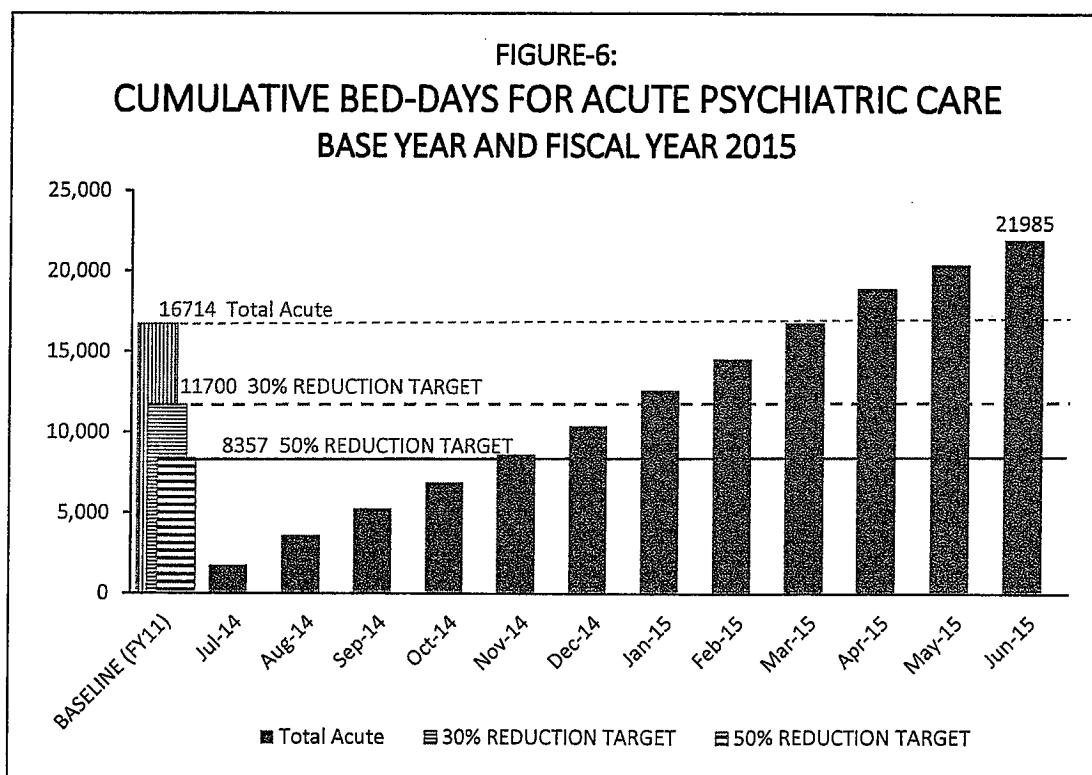
¹³ In the past, these data have been broken out by the State division responsible for oversight (DSAMH and DMMA); given the changes since January 1, 2015, this differentiation is no longer relevant.

¹⁴ It is noted that the State is now analyzing data with respect to individuals transferred to DPC from IMDs (e.g., because they could not be stabilized within a short period in those settings), and those moving from acute-care

181 were managed through DMMA (15,510 out of 17,771). As is explained later (and detailed in
 182 prior Monitor reports), at least a part of these increases may have been due to the State's lack of
 183 appropriate controls over the process by which individuals whose behavioral healthcare was
 184 managed through MCOs were referred to DSAMH for the specialized services and housing
 185 required by the Agreement that can reduce the vulnerability for hospitalization. The protocols for
 186 such referrals and lines of accountability have been significantly improved since January 1,
 187 2015. However, acute bed-days have continued to rise this calendar year. Given this pattern of
 188 increasing hospital use, plans that are now being discussed to further expand hospital capacity by
 189 building a new IMD in southern Delaware¹⁵ raise additional questions as to whether the State
 190 will be able to curtail hospital rates for the target population.

191 Figure-6 presents the data contained in Figure-5 on a cumulative basis, that is, not as
 192 monthly totals, but as running totals for the fiscal year. This presentation allows ready analysis
 193 of bed use against the 30% and 50% reductions (from the base year) that are specified in the
 194 Agreement.

195



status to intermediate-status in DPC to ensure that the above data correctly reflect the entire duration of an individual's hospitalization episode.

¹⁵ The proposal that has been shared with the Monitor calls for a 90-bed hospital. Although the full plan for this facility has not yet been completed, it is noted that conditions for approval include requirements to prevent the unnecessary admission of individuals and to collaborate with DSAMH and its network of community providers to ensure least-restrictive treatment and service continuity.

196 This chart shows that last fiscal year the State's total overall bed-day use met and
 197 exceeded the 50% reduction level (which is to be met by July 1, 2016 per Section III.D.4 of the
 198 Agreement) in November 2014, with seven months still remaining in the fiscal year. By January
 199 2015—with five months remaining in the fiscal year—it had already exceeded the 30% reduction
 200 level which was to have been met in July 2014 (Section III.D.3). And in March 2015 it had
 201 almost reached the point of utilizing the full Baseline bed-use from which these reduction targets
 202 are calculated. By the end of the 2015 fiscal year, the State reported 21,985 acute care bed days,
 203 which is greater than a 30% increase in acute care bed use by the target population, relative to
 204 the Baseline year. These increases not only run counter to the requirements of the Agreement,
 205 but they raise systemic issues of quality and performance. As is discussed in the section of this
 206 report relating to Quality Assurance and Performance Improvement, the State is not taking
 207 appropriate advantage of data that could clarify the characteristics of the population responsible
 208 for bed-use increases, as well as their utilization of services earlier on that could reduce their
 209 hospitalization rates.

210

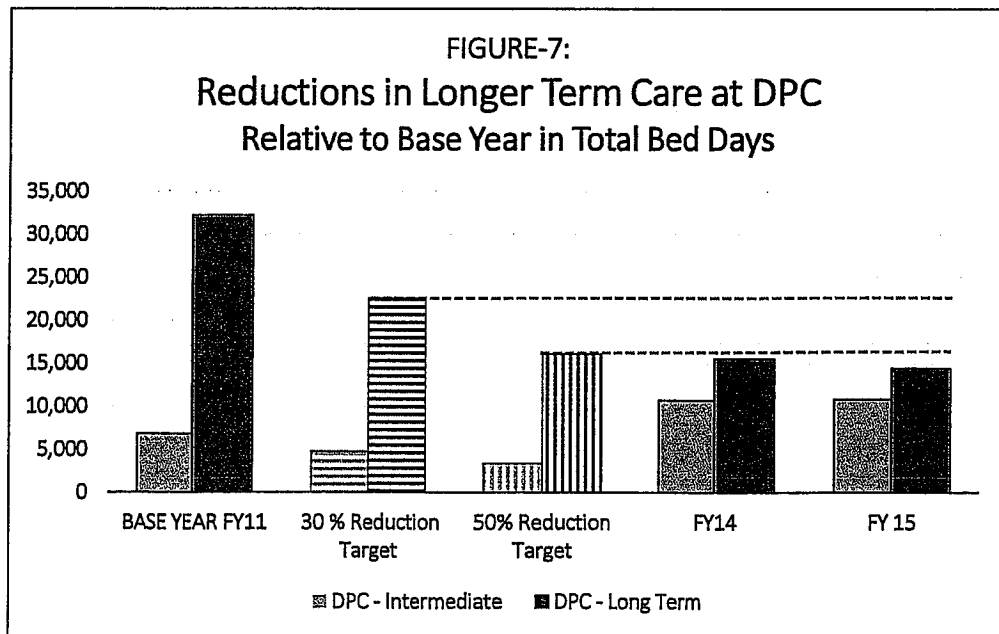
211 Additional Factors

212 In assessing the State's performance with regard to Crisis Stabilization provisions of the
 213 Agreement, there are some additional factors worth noting.

214

215 *Reductions in Longer-Term Care at DPC*

216



217

218 Figure-7 presents data demonstrating the State’s success in reducing reliance on long
219 term care at DPC. Applying the 30% and 50% reduction targets which the Agreement contains
220 with respect to acute care to longer term care at DPC, the State is performing much better.¹⁶ The
221 State defines “acute care” as hospitalization lasting 14 days or fewer. “Intermediate” term care at
222 DPC is defined as lasting 15 to 179 days and “long term” hospital care is defined as longer than
223 179 days. As is reflected in this chart, the State has dramatically reduced bed-days in long term
224 care, meeting a 50% reduction target in both fiscal years 2014 and 2015. These rates have
225 remained stable for some time. Whereas DPC used approximately 40,000 bed days for
226 intermediate- and long-term care in the base year, as of fiscal year 2015 the combined total for
227 these categories of care was only about 25,000 bed days—a reduction of about 38%.

228

229 *Referrals for Specialized Mental Health Services*

230 Prior Monitor reports have described significant problems in the State ensuring that
231 members of the Agreement’s target population whose behavioral healthcare was managed
232 through DMMA were being appropriately referred to DSAMH for the specialized services and
233 housing required in the Agreement. The arrangements that had been in place for years were
234 wholly unclear not only as to what entity was responsible for making such referrals—the IMD,
235 the MCO, or DMMA—but even what criteria would be applied for determining that such
236 referrals were necessary.

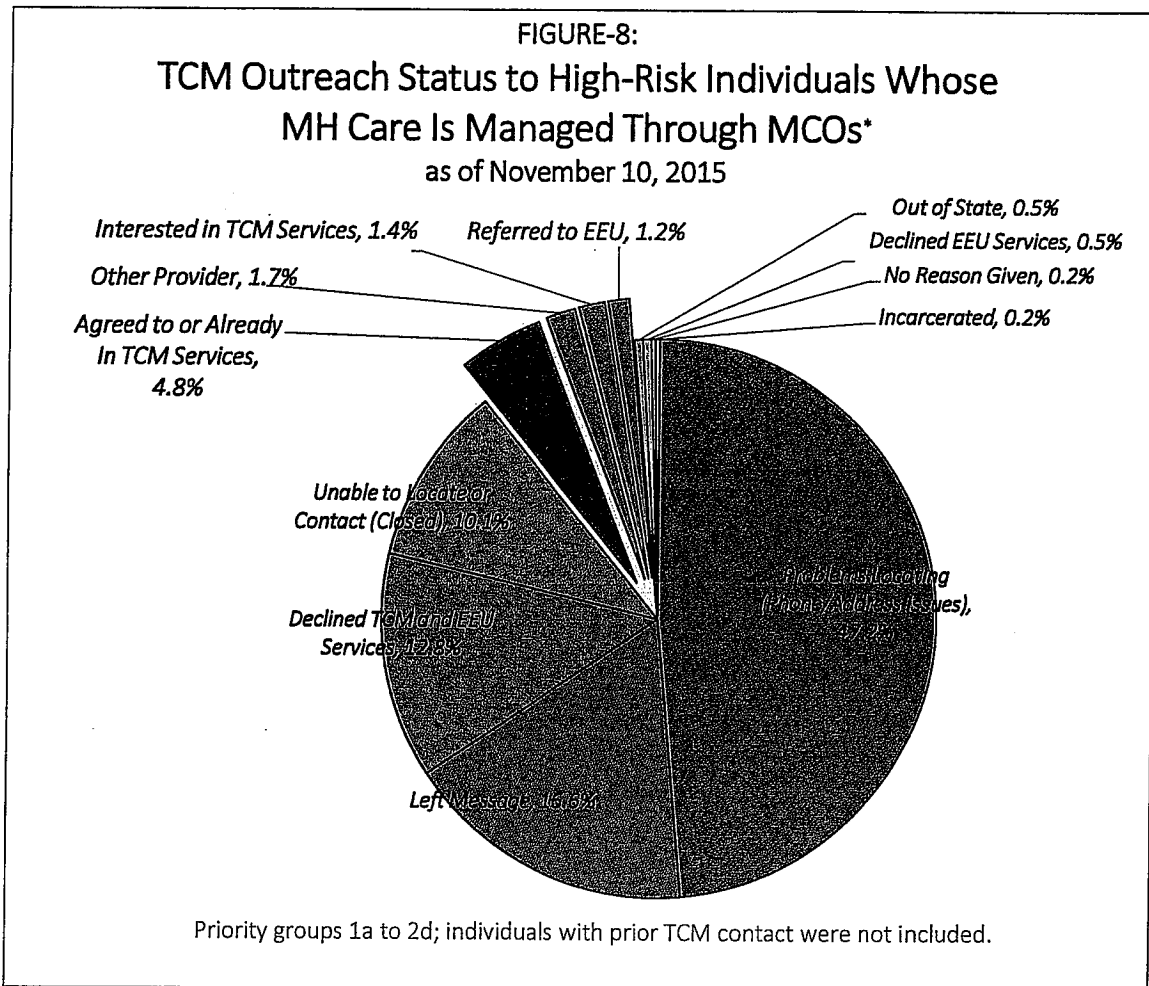
237 As was discussed in the Monitor’s last report, the State identified a group of 454
238 individuals with SPMI who had not been referred for specialized services even though they were
239 obviously not doing well in the community, as evidenced by multiple re-hospitalizations in IMDs
240 in a short period of time. That report described an initiative by the State that was launched in
241 March 2015 to reach out to these ostensibly very high-risk individuals, including through phone
242 contact and in-person visits, to ascertain their wellbeing and to make specialized services
243 available to them. For reasons that are not at all clear, the State delayed action on this initiative,
244 thereby further lengthening the time between individuals’ hospital discharge and the outreach to
245 offer specialized services. Accordingly, it was unable to make contact with a large proportion of
246 this group of 454 (had referrals been made routinely as a part of discharge planning at the IMDs,
247 this would not have been an issue). Once the initiative got underway, however, the State made a
248 good-faith effort using Targeted Care Managers (TCM) to attempt to connect with each of these
249 individuals.

250 Figure-8 summarizes the outcomes of this effort, as well as the detailed data the State
251 maintained to track its progress. Notwithstanding their intensive efforts, the TCM staff were able
252 to make contact with only about 23% of the group; they were unable make contact with about
253 77% of this group. With respect to those actually contacted, about 13% of the group of 454
254 declined the offer of services and just under 10% were brought to some level of either receiving
255 services or enrollment in services. For those individuals not among those on track to be served
256 (and who are still in the State’s Medicaid program), the applicable MCOs have been notified of

¹⁶ Such targets for long-term care, however, are not a part of the Agreement.

257 their high-risk status so they can pursue referrals should opportunities present themselves in the
258 future.

259



260

261 In addition, as a part of the new collaboration agreements that went into effect this
262 calendar year, DSAMH, DMMA and the MCOs now have specific criteria—for instance,
263 hospital readmission—that trigger a referral for specialized services. The State has created a
264 tracking dashboard with such measures as the number of monthly hospital admissions, the status
265 of these individual relative to PROMISE/DSAMH, and the number of individuals not receiving
266 specialized services who are referred. While the numbers are still preliminary, there has already
267 been a significant increase in referrals of individuals with SPMI who had not been receiving
268 these services. It is too soon to say whether this effort will have the effect of reducing the
269 number of inpatient days used by the target population.

270

DPC report critical of state

Monitor questions court commitments

By Beth Miller
The News Journal

Delaware courts are ordering too many people with mental illness to out-patient commitment – an involuntary treatment status – and the rate of such orders increased in 2012, according to the court-appointed monitor of the state's progress in revamping its mental health services.

The practice – which dates back more than half a century – is vague, not covered by Delaware law and largely unsupervised, state officials acknowledged Tuesday. And its continuing use points to underlying problems in the system, according to Robert Bernstein, an expert in civil rights issues for those with disabilities who was appointed by U.S. District Court to evaluate Delaware's reforms.

Delaware has until 2016 to meet terms of a sweeping settlement with the U.S. Department of Justice, which sued the state after finding violations of civil rights at the Delaware Psychiatric Center. The DOJ's investigation was prompted by a series of reports in The News Journal about conditions at the

See REPORT, Page A2

Report: Delaware's reform effort continues

Continued from Page A1

ate's largest inpatient psychiatric hospital.

Overall, Bernstein has raised the state's comprehensive work in transforming mental health services, providing expanded resources in crisis response and community-based care, and helping long-term patients at DPC find new homes in the community.

His most recent report the third since the settlement was signed in July 2011 — calls the state's work innovative and diligent and notes "important progress" on several fronts.

Court-ordered treatment is off the charts, though — more than six times New York's rate — and it increased by 28 percent during the last half of 2012, he said.

Using the court to force treatment is an emergency-only approach elsewhere, Bernstein wrote, while the practice here suggests a variety of systemic incentives, including financial, convenience and the belief that discharging someone might help a provider avoid liability risks, he said.

Bernstein said interviews with court observers showed the commitment-related court hearings lasted about five minutes, relied on the recommendation of a doctor who had not treated the person, and often included an attorney who agreed to whatever that doctor said.

Also troubling was Bernstein's report that



The U.S. Department of Justice required changes in mental health treatment after abuses were uncovered at the Delaware Psychiatric Center. SUCHAT PEDERSON/NEWS JOURNAL FILE

group's subcommittee on outpatient commitment. The practice, he said, relies on a "convalescent" status mentioned in Delaware law that — decades ago — provided care for those who were not considered ready for complete release.

"It's highly outdated and it's significantly overused," Hewlett said. "We push for highly limited forced treatment in any capacity because that really isn't what is going to help the person recover. They only recover when they have an investment in their treatment and it takes an awful lot of outreach to

communicate with the person, engage with the person and get them to go along with treatment." Hewlett said if a person is considered a threat to self or others they should be committed to inpatient care. Otherwise, he said, no one should be forced to submit to treatment.

Hewlett's view is controversial. Some psychiatrists and specialists argue that it is better to force a person into treatment — helping them get stabilized — than to let them get sicker until they must be hospitalized.

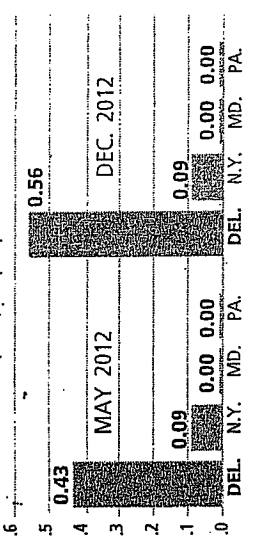


Kevin Huckshorn, director of the state Division of Substance Abuse and Mental Health, said the state is asking providers to identify those who are unnecessarily on outpatient commitment and to take them off the list.

Kevin Huckshorn, director of the state Division of Substance Abuse and Mental Health, said the state is asking providers to identify those who are unnecessarily on outpatient commitment and to take them off the list.

ACTIVE OUTPATIENT COMMITMENT ORDERS

Outpatient commitment is a court order for treatment of a mental illness. It is involuntary, as is inpatient commitment. Unlike three neighboring states, court-appointed monitor Robert Bernstein says Delaware's use of outpatient commitment is both far more common and increasing. Below are outpatient commitment orders per 1,000 people.



SOURCE: Robert Bernstein, Third Report of the Court Monitor on Progress Toward Compliance with the Agreement U.S. v. State of Delaware THE NEWS JOURNAL

She said. Horizon House was able to get 70 people off those lists.

Overall, more than 2,000 people were on such commitments at some point or another last year, Huckshorn said, with 500 to 600 at any given time.

The problem is worsened when someone is ordered, for vague reasons, into unspecified treatment without additional assistance to promote compliance.

"There is an assumption that there was oversight or special treatment," she said, "when in truth, there really isn't. Only that in some specified time — two weeks, a month, six months — they must come back to court."

When they don't show up in court — either because they don't realize they must or because they are still sick — their problems get worse.

Huckshorn said she was not surprised that Bernstein flagged the issue. It has been apparent to her since she arrived in the state in 2009 to work

on systemic reform.

"Not until we started drilling down on the numbers and Bob was able to find data on the rates in other states did we become aware of how out of whack we were," she said. "The chart was kind of shocking."

The state will address the problem, she said. Likely changes would require that only treating psychiatrists can petition a court on behalf of their patients, would require clear descriptions of behaviors that demonstrate a danger to self or others and include clearly defined time periods.

The state's reform effort continues, largely with Bernstein's endorsement and applause.

"We're in a good place, working together," Huckshorn said. "It's a messy, slow process. But that's the way system change happens."

Contact Beth Miller at 324-2784 or bmillier@delawareonline.com. Follow on Twitter @BMiller57

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UNPUBLISHED OPINION. CHECK COURT
RULES BEFORE CITING.

Court of Chancery of Delaware.
In the Matter of J.T.M., A disabled person

C.M. No. 17901-S
Date Submitted: October 24, 2014
Date Decided: December 31, 2014

MEMORANDUM OPINION

GLASSCOCK, Vice Chancellor

*1 This Opinion involves whether a guardianship should be imposed for the benefit of J.T.M., an eighteen-year-old man resident in Delaware. Following a hearing on October 24, 2014, I imposed a guardianship appointing D.S., Mr. M.'s great-grandmother, and W.M., his father, as co-guardians. An Order was entered on that date; this Opinion supplements that Order.

Our country was founded on principles of individual rights, self-governance and self-determination. This is embodied in our founding documents, including the Declaration of Independence^{FN1} and the Bill of Rights.^{FN2} The Delaware Constitution of 1897 also makes clear the importance of such rights.^{FN3} An entire branch of our jurisprudence, the criminal law, is dedicated to achieving a balance between the exercise of these rights and the interest of the State in protecting persons and property. That body of law, together with its governing constitutional provisions,^{FN4} allows restriction or termination of those rights through incarceration or execution, but only with significant procedural safeguards and after determination of guilt beyond a reasonable doubt.^{FN5} Outside of the criminal arena, imposition of a guardianship represents the most significant deprivation of the right to self-determination a court can impose.^{FN6} This case represents a first chance to address the proper

standard by which evidence of the need for a guardianship must be established.^{FN7}

FN1. The Declaration of Independence para. 2 (U.S. 1776) ("We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness.")

FN2. *See, e.g.*, U.S. Const. amend. V, XIV.

FN3. *See, e.g.*, Del. Const. pmb1: ("Through Divine goodness, all people have by nature the rights of worshiping and serving their Creator according to the dictates of their consciences, of enjoying and defending life and liberty, of acquiring and protecting reputation and property, and in general of obtaining objects suitable to their condition, without injury by one to another; and as these rights are essential to their welfare, for due exercise thereof, power is inherent in them; and therefore all just authority in the institutions of political society is derived from the people, and established with their consent, to advance their happiness; and they may for this end, as circumstances require, from time to time, alter their Constitution of government.")

FN4. *See, e.g.*, U.S. Const. amend. V, V, VI, VIII, XIV; Del. Const. art. I, §§ 6, 7, 8, 11, 12.

FN5. *See, e.g., In re Winship*, 397 U.S. 358, 364 (1970) ("Lest there remain any doubt about the constitutional stature of the reasonable-doubt standard, we explicitly hold that the Due Process Clause protects the accused against conviction except upon proof beyond a reasonable doubt of

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every fact necessary to constitute the crime with which he is charged.”); *see generally Mathews v. Eldridge*, 424 U.S. 319, 332 (1976). (“Procedural due process imposes constraints on governmental decisions which deprive individuals of ‘liberty’ or ‘property’ interests within the meaning of the Due Process Clause of the Fifth or Fourteenth Amendment.”)

FN6. *See, e.g., Alison Patrucco Barnes, Beyond Guardianship Reform: A Reevaluation of Autonomy and Beneficence for A System of Principled Decision-Making in Long Term Care*, 41 Emory L.J. 633, 736 (1992). (“The restriction of liberty created by appointment of a substitute decision-maker is severe. The rights enjoyed by all competent adults to associate with persons of their choice, to engage in recreational, political, and religious activities, and to choose their care providers can be controlled by the substitute decision-maker.”); Susan G. Haines & John J. Campbell, *Defects, Due Process, and Protective Proceedings: Are Our Probate Codes Unconstitutional?*, 33 Real Prop. Prob. & Tr. J. 215, 227 (1998). (“The constitutionally protected individual interests implicated in a guardianship proceeding include: the right to choose where to live and with whom to associate; the right to make medical decisions regarding one’s body; the right to marry and to associate freely; the right to travel or pursue in privacy the activities of daily living; and the right to be free from unwanted constraints or incarceration.”); Jennifer L. Wright, *Protecting Who from What, and Why, and How?: A Proposal for an Integrative Approach to Adult Protective Proceedings*, 12 Elder L.J. 53, 71 (2004). (“A guardianship results in the reduction of the protected person to the status akin to that of a minor child. The protected person loses the right to deter-

ine where he or she will live, whom he or she will see, where he or she will go, and how he or she will live his or her life.”) (footnote omitted).

FN7. I do not mean to imply this is a case of first impression. Out of respect for the privacy rights of individuals potentially subject to guardianships as disabled persons, these proceedings are confidential. Accordingly, judicial decisions in these cases are not publicly disseminated or, as in the public version of this Opinion, the names of the participants are redacted. This is, therefore, the first public Opinion to address the proper standard of review under our current guardianship statute. I am indebted to Vice Chancellor Noble, whose careful scholarship as expressed in a non-public decision of this Court has served me as a guide.

*2 Because it involves fiduciary relationships, guardianship has traditionally fallen within the jurisdiction of this court of equity, both with respect to its English common-law antecedents and in its current statutory incarnation. Today, all guardianships imposed in Delaware over disabled adults are pursuant to statute. The Court of Chancery is empowered by 12 Del. C. § 3901(a) “to appoint guardians for the person or property, or both, of any person with a disability.” A “person with a disability” is one who

[b]y reason of mental or physical incapacity is unable properly to manage or care for their [sic] own person or property, or both, and, in consequence thereof, is in danger of dissipating or losing such property or of becoming the victim of designing persons or, in the case where a guardian of the person is sought, such person is in danger of substantially endangering person’s own health, or of becoming subject to abuse by other persons or of becoming the victim of designing persons[.]^{FN8}

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FN8. 12 *Del. C.* § 3901(a)(2).

The Petition here was filed by W.M. ("W.") and D.S. ("D."),^{FN9} the father and great-grandmother of Mr. M., respectively. In compliance with Court of Chancery rules, the Petition was accompanied by an affidavit from Mr. M.'s treating physician.^{FN10} According to that affidavit, Mr. M. suffers from "a disability that interferes with the ability to make or communicate responsible decisions regarding health care, food, clothing, shelter or administration of property," caused by autism, attention deficient hyperactive disorder, and encephalopathy.^{FN11} As a result of this disability, Mr. M. "is unable to perform the following functions: (1) Activities of daily living; (2) Cognitive activities, e.g. needs help with dressing, brush[ing] teeth and hygiene, poor judgment."^{FN12} In the opinion of the physician, despite his disability, Mr. M. has sufficient mental capacity to understand the nature of guardianship and to consent to the appointment of a guardian.

FN9. I use the first names of the Petitioners to differentiate them from the proposed ward, Mr. M. No disrespect is intended.

FN10. *See* Ct. Ch. R. 175(d).

FN11. Aff. of Thiele Anthony, MD.

FN12. *Id.*

Consistent with the procedures established by Rule 176,^{FN13} an attorney was appointed *ad litem* for Mr. M. That attorney, Andrew A. Whitehead, Esquire, interviewed his client, Mr. M., at his office in Georgetown on October 8, 2014. He also reviewed the physician's affidavit and met with the Petitioners. In a thoughtful report to the Court, Mr. Whitehead opined that his client was a disabled person under the provisions of 12 *Del. C.* § 3901(a). He reported that Mr. M. consented to and supported the appointment of his father and great-grandmother as his guardians. The Petitioners disclosed to Mr. Whitehead that Mr. M. receives So-

cial Security Disability benefits in cash each month as well as benefits under Medicaid. He lives with D. during the week, as he has for many years, and attends a day program to educate those with autism spectrum disorder. During weekends, Mr. M. lives with W. At both residences, he has his own room and feels "at home." He also spends one weekend a month with his mother, who lives in another state. The report explains that Mr. M. "was diagnosed with autism at a very young age and has been in [an academic autism program] since he was three years old." The guardians explained to the attorney *ad litem* that Mr. M. could not comprehend the value of money, that he has been tricked out of toys and other property by children in his neighborhood, that he could not grasp budgeting and struggles with counting money, and that he suffers from anxiety under stress. Further, he is unable to take his required medications except under direction of others. Mr. Whitehead supports appointment of W. and D. as guardians for Mr. M.

FN13. *See* Ct. Ch. R. 176(a).

I. STANDARD OF REVIEW

*3 To impose a guardianship, I must find that, by reason of mental or physical incapacity, the proposed ward is "unable to properly manage or care for [his] own person or property," and that as a result, he is "in danger of dissipating or losing such property or of becoming the victim of designing persons or, in the case where a guardian of the person is sought, such person is in danger of substantially endangering the person's own health...."^{FN14} The statute, however, is silent as to the standard by which this finding must be made. As described above, the criminal law requires proof beyond a reasonable doubt before substantial deprivations of personal liberty interests may be imposed by the Court; at least one state imposes this standard to guardianship as well.^{FN15} The United State Supreme Court, on the other hand, has held that certain governmental actions that limit individual rights of self-determination and self-control, such as termination of parental rights, civil commitment,

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deportation, and denaturalization, must be supported by evidence that is clear and convincing.^{FN16}

The imposition of guardianship is, I find, even more restrictive of substantial liberty interests than those actions. Indeed, the majority of states impose a clear and convincing evidentiary standard for establishing a guardianship by statute.^{FN17} While Delaware's cases have not been consistent in the application of a standard, I find that imposition of a guardianship must be supported by evidence that is clear and convincing, and not merely by a preponderance of the evidence.

FN14. 12 *Del. C.* § 3901(a)(2).

FN15. See Sally Balch Hurme and ABA Comm'n on Law and Aging, *Conduct and Findings of Guardianship Proceedings (2013)*, available at http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_CHARTConduct.authcheckdam.pdf; see, e.g., *In re Kapitula*, 899 A.2d 250, 253 (N.H.2006) (Findings justifying imposition of a guardianship must be "in the record and must have been based upon evidence supporting them beyond a reasonable doubt.").

FN16. These decisions have been made in the context of the due process clause of the Fifth and Fourteenth Amendments. See *Santosky v. Kramer*, 455 U.S. 745, 747-48 (1982) ("Before a State may sever completely and irrevocably the rights of parents in their natural child, due process requires that the State support its allegations by at least clear and convincing evidence."); *Addington v. Texas*, 441 U.S. 418, 424 (1979) ("We noted earlier that the trial court employed the standard of 'clear, unequivocal and convincing' evidence in appellant's [civil] commitment hearing before a jury. That instruction was constitutionally adequate. However, determination of the precise burden equal to or greater

than the 'clear and convincing' standard which we hold is required to meet due process guarantees is a matter of state law which we leave to the Texas Supreme Court."); *Woodby v. INS*, 385 U.S. 276, 286 (1966) ("We hold that no deportation order may be entered unless it is found by clear, unequivocal, and convincing evidence that the facts alleged as grounds for deportation are true."); *Chaunt v. United States*, 364 U.S. 350, 353 (1960) ("[I]n view of the grave consequences to the citizen, naturalization decrees are not lightly to be set aside—the evidence must indeed be 'clear, unequivocal, and convincing' and not leave 'the issue in doubt.'") (citation omitted).

FN17. Sally Balch Hurme and ABA Comm'n. on Law and Aging, *Conduct and Findings of Guardianship Proceedings*, *supra* note 15.

At the hearing on October 24, 2014, I was able to question Mr. M. as well as D. and W. I reached the same conclusion as did the attorney *ad litem* on behalf of Mr. M. All the evidence indicates that Mr. M. has cognitive disabilities that make him unable to manage his own property, make him subject to designing persons and place him at risk of serious physical harm if his consumption of medication is unsupervised. Although he is disabled, Mr. M. can comprehend the nature of a guardianship and supports its imposition here as in his best interest. He clearly loves and trusts the Petitioners, and they in turn love him. Mr. M.'s mother supports the guardianship, which is in all respects uncontested. Mr. M., who is by all accounts a pleasant and likeable young man, is indeed fortunate to have a loving family to support and assist him. I find, by clear and convincing evidence, that Mr. M. is a disabled person subject to guardianship under 12 *Del. C.* § 3901(a)(2).

II. CONCLUSION

For the reasons above, the Petition for Guardi-

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anship is granted. I further find that that the Petitioners are the appropriate persons to serve as Mr. M.'s guardians and that the guardianship is plenary.
FN18 In this particular instance, the record indicates clearly that Mr. M. is unable to manage his property or health care and that it is appropriate, consistent with the discussion above, that the use of his resources and his place of residence and living conditions be as decided by his guardians in his best interest. However, Mr. M. is a very young man still in school and, I expect, learning and growing intellectually and emotionally. As a result, I direct the Office of the Public Guardian to provide me with a report in one year concerning Mr. M.'s condition and whether any aspects of the guardianship should be modified.
FN19 An Order consistent with this Opinion has already been placed on the docket.

FN18. *See* 12 *Del. C.* § 3922.

FN19. The required report from the Office of the Public Guardian shall not relieve the guardians of providing a yearly physician's report in twelve months as required by Court Rule. *See* Ct. Ch. R. 180-B.

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Nearly half of Delaware residents over 35 are caregivers



Jen Rini, The News Journal

9:38 p.m. EST January 19, 2016



(Photo: WILLIAM BRETZGER/THE NEWS JOURNAL)

When Carol Barnett was 11, she told her mother to send her 3-year-old brother, Steve, "back where he came from," in typical, sassy preteen fashion.

But today, Barnett, 60, can't imagine life without him.

Steve was born with cerebral palsy, a disorder that affects his muscles and the way he moves.

Carol has been caring for Steve consistently for the past 30 years.

She is not alone by a long shot. Nearly half of all Delawareans over age 35 provide – or have provided – unpaid long-term care for a loved one who is ill, elderly or lives with a physical or mental disability, according to survey from AARP. Caregivers could be relatives, neighbors and friends.

Long-term care can also be for helping someone with a chronic illness or recovery from a serious accident.

Their parents died within eight years of each other, so when Carol was 25 and Steve was 17, the two of them had to quickly come up with a plan for Steve. Though he is very smart – ask him any fact about baseball – he needs help performing daily tasks.

As he was entering adulthood, the big questions were: Can he live on his own and where would he work?

"It was a real eye-opener," Carol said. "I don't remember there being a lot of time for grieving."

Now, there is a legislative push to acknowledge a caregiver's role, specifically when a loved one is admitted to a medical facility. Dubbed the CARE Act, the initiative, spearheaded by AARP of Delaware, will require three specific provisions:

- When a loved one is admitted to a hospital, the name of the family caregiver will be reported.
- The family caregiver will be notified if their loved one is discharged to another facility or back home.
- The caregiver will be taught any new medical tasks that will be provided at home and will be included in the action plan post-discharge.

"It's really a benefit for the whole system," said Sheila Grant, associate state director of advocacy for AARP of Delaware. It will help caregivers be more confident as well. "It's definitely a national trend," she said.

AARP began lobbying lawmakers and other community partners about the initiative. So far, 18 states have passed similar legislation.

Sen. Bethany Hall-Long, chair of the Senate Health Committee and nursing professor at the University of Delaware, who plans to sponsor the proposed measure, said the legislation will recognize "the value of caregivers." Most care is delivered in the community and in the home, she said, and caregivers face many stressors.

"It really gives a means to benefit patient care," she said. "It's a great initiative. We will certainly want to work with all the hospital associations," she added.

The Delaware Healthcare Association, which represents hospitals in the state, is staunchly against the measure.

Wayne Smith, president of the association, said the legislation is "absolutely not needed," and both the federal Centers for Medicaid and Medicare and hospital accrediting body the Joint Commission already have provisions in place to help caregivers that include sharing information and providing in-hospital training.

While the association does support caregivers, Smith said the state legislation just adds another layer of superfluous reporting and could increase costs to hospitals. It would be like asking the state to "require their citizens to pay their taxes."

The topic of caregiving has been a hot issue. About 45 percent of Delawareans over 35 have helped a loved one at some point with tasks such as shopping, household chores, transportation, medication management or nursing.

Recognizing the growing burden, the Legislature commissioned the Family Caregiving Task Force in 2014.

The group's report, titled Caregiver Support: Blueprint for Delaware, included legislative recommendations related to discrimination against caregivers in the workplace, establishing tax credits for certain caregiving expenses and increasing the length of allowable leave beyond 12 weeks.

The first step, AARP says, is to pass the CARE Act in Delaware this legislative session.

Family caregivers help with bathing, dressing, preparing meals, administering medications and act as chauffeur to daily activities or doctors' appointments.

And that care is not cheap: In 2013, family caregivers in Delaware provided 114 million hours of care to loved ones, which is estimated to be worth about \$1.58 million. Nationally, the cost of unpaid care during that same time period rose to \$470 billion.

When Steve moved in with Carol in early 2000, she spent over \$15,000 renovating the porch of her Wilmington home into a room so her brother would have access to more space.

"People are going to have to work it [caregiving] into their budget like buying groceries," Carol said.

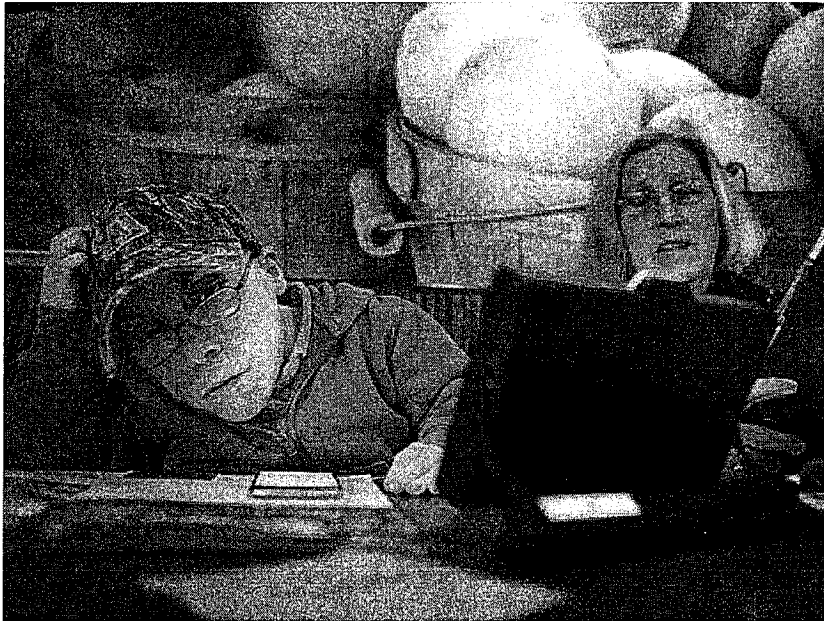
Finding the new normal

Like the Barnetts, the MacDonald family had to confront caregiving.

Lizzy MacDonald, of Dover, is a little person. Born with a condition of dwarfism called spondyloepiphyseal dysplasia, she was hospitalized for the first 10 months of life.

In those first few years, her mom, Beth, would ask herself, "Is she going to be alive?"

Buy Photo



Lizzy MacDonald of Dover, is born with the condition dwarfism or skeletal dysplasia and had to stay in the hospital for the first 10 months of life. (Photo: SUCHAT PEDERSON/THE NEWS JOURNAL)

Now at 26, there's no question. Lizzy, a self-proclaimed tomboy, is a spitfire out to pave her way in the world.

Lizzy graduated from Delaware Technical Community College in Dover three years ago with a degree in human services. Though she had an aide with her from kindergarten through high school, she attended college without one.

Her mother, Beth, was by her side for most classes and would take her to and from campus. Lizzy said people would ask if she was sure she wanted to pursue that major. They'd even ask whether or not she did her homework without any help.

"I took college prep in high school," Lizzy said over appetizers at Applebee's in Camden, still incredulous by the questions.

They've also made their lives more accessible. They finally have a wheelchair-accessible van and the downstairs has been restructured to make it easier for her to be independent.



Lizzy MacDonald, 26, and her mother Beth arrive at Applebee's in Camden for dinner. (Photo: SUCHAT PEDERSON/THE NEWS JOURNAL)

Lizzy's area in the kitchen has a microwave, refrigerator and coffee-making station, decorated with Redskins and other sports memorabilia. Plumbers installed a garden sink into their downstairs bathroom so she could bathe on her own. Her grandfather built steps for her to reach the toilet.

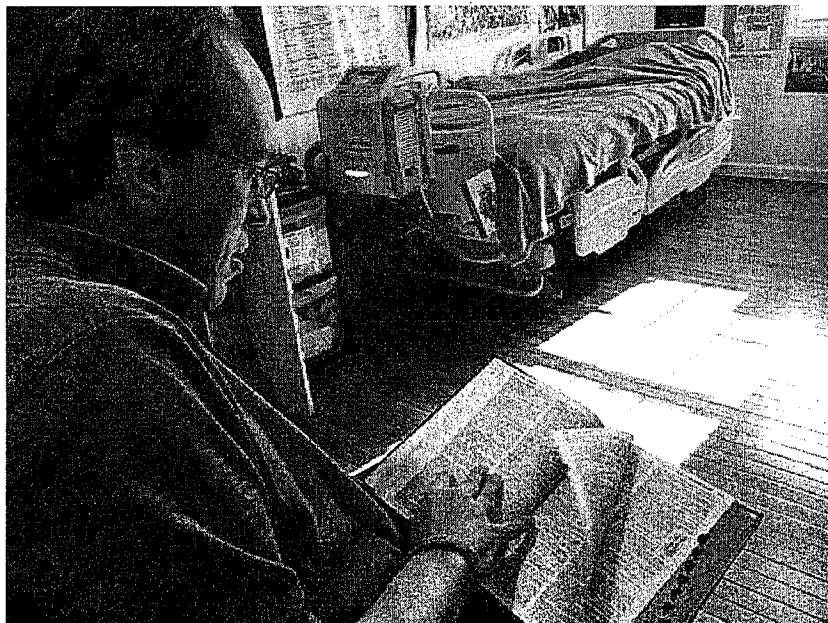
"It took 22 years for her to have her privacy," Beth said.

Ann Phillips, on the other hand, had a different introduction to caregiving.

A car accident left her son Aaron Deede with traumatic brain and spinal cord injuries at age 18.

"Overnight we became caregivers instead of empty-nesters," Phillips, of Wilmington, recalled.

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Aaron Phillips, of Wilmington, with one of his favorite books: a dictionary. Aaron lives with a brain injury, takes about 24 medications and needs a caregiver daily. (Photo: Jen Rini/The News Journal)

Ann and her husband Larry were married for three years when Aaron had the accident. She left her job and Larry took early retirement to be home to help him 24/7.

"I had no idea about caregiving," Ann said. "I really was very naïve about it and thought that the services would be at my fingertips. I had made all kinds of promises to him when he was in a coma about his quality of life."

When he first came home from the hospital, Aaron had to be turned every two hours to make sure he was comfortable. The family's two-car garage had to be quickly converted so his bedroom could be moved to the first floor. Aaron had to relearn how to swallow, how to speak and how to use the bathroom.

"I wasn't getting sleep," Ann said.

In addition to getting up to speed with Aaron's new medical responsibilities, she had to quickly learn how to apply for funding and search for insurance plans to help cover the cost of medication, activities, treatment and additional help.

Learning the lingo, such as what is respite care, was imperative. Someone once told her: "If you don't know what it is, then you don't need it."

She learned that respite care provides temporary, short-term breaks to those who are caring for family members.

Ann realized that she wanted to make it her mission to help fellow caregivers navigate the resources that are out there so she started the organization Delaware Family Voices.

"Families tell me you have to piece together your own services," Ann said. "You have to ask people to explain things. ... Don't pretend you know."

"I have found that parents of children feel more guilty saying they need help because they feel it's their job," Ann said. "The caregiving for somebody with special needs is much more than the typical parenting."

With all the coordinating, caregivers are facing incredible burnout from the daily demands, explained Verna Hensley, vice president of public affairs for Easter Seals Delaware and Maryland's Eastern Shore Easter Seals. The organization provides services and support to children and adults with disabilities or special needs and their families, such as loans to purchase assistive technology such as wheelchair ramps for vans.

To avoid burnout, or other health problems, respite care in particular is needed.

But respite-funded spaces at certain facilities can be scarce. Last year Carol, for instance, had to call in March to secure a spot in the fall for Steve at the Mary Campbell Center, a residential facility for adults and children with disabilities.

Even though the time may be limited, every bit counts.

"That's why I go to Mary Campbell, so [Carol] doesn't kill me," Steve joked.

Over 200 people secured respite care with the help of Easter Seals in the last year. Through August 2015, Easter Seals helped over 300 caregivers through the organization's Caregiver Resource Center.

"Every year we get funding through the state. Every year we run out of money very quickly," said Nancy Ranalli, director of community outreach and assistive technology for Easter Seals.

Funding for the respite care program typically costs Easter Seals \$65,000 and families can apply for about \$500.

Joyce Medkeff, caregiver case manager for the resource center, is on call to help people figure out how to search for at-home medical aides and how to apply for respite care.

"When I talk to someone I try to send them resources very particular to their situation rather than them having to search the Internet," Medkeff said.

"I do all that legwork for them. It takes a little bit of the stress off."

"I think one of probably the biggest problems in caregivers obtaining services is finances," Medkeff said. "There are a lot of services out there. They have to pay out of pocket. Sometimes people have to quit their jobs."

Adapting and changing

Carol likes to say Steve was born too early. He has some struggles, but loves being in the community, she said. The pair often explore the Wilmington Riverfront, seeing movies and trying new restaurants – as long as they have ADA accommodations.

After years working in the banking industry doing data entry, Steve landed the perfect gig: as one of the ticket takers at the Wilmington Blue Rocks stadium.

He's a self-professed Dallas Cowboys fan and a diehard baseball fan. He and Carol went to spring training in Florida for 15 years and he even coached a Little League team for children with special needs. Friends know to send baseball-themed cards on his birthday.

So why the love for baseball? "The ritual," he says.

Even though they have their routine, Carol said that caregivers, like herself, always need to be thoughtful and thinking ahead.

Caregivers have to think of a plan B for their loved one, in case something happens to them.

"It's tough. People don't talk about this stuff," she said.

Beth MacDonald admits that it can be hard to let Lizzy go out on her own.

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Lizzy McDonald, a self-proclaimed tomboy, says people confuse her being a young child when she goes shopping with her mother. (Photo: SUCHAT PEDERSON/THE NEWS JOURNAL)

"It's hard to take that safety hat off," Beth said. "You don't want to put them in danger."

It's even more difficult to talk about what happens if Beth were to get sick or pass on. Right now, she is with Lizzy every day helping her in little ways, such as stocking the fridge, or in bigger ways like driving her to activities.

"A lot of people don't have the conversation," Beth said. "Because you think you always have time."

Ann Phillips' husband Larry got a taste of the work she does when she had to have surgery the same time as Aaron.

Larry went back and forth from their home in Wilmington to take care of Ann, back to Thomas Jefferson Hospital in Philadelphia to be with Aaron.

"I felt intimidated because I can't replace you (Ann)," Larry said.

Ann said they have plans in place, but caregiving long-term is still a concern. For the time being, they focus on the present to make Aaron's life as full as possible.

"He had a life before and dreams, I just wanted to figure out how to adapt them," Ann said.

Before his accident, Aaron Deede wanted to be a playwright. One of his early works, a one-act piece called Accidents Do Happen, was performed in

He still loves acting and participates in plays through the organization Acting Without Boundaries in Pennsylvania. There are practices once a month, every Sunday, in preparation for summer and fall plays.

This summer, the play is the Jungle Book.

Even with a spinal and brain injury, Aaron still loves words. Ann first gave him a dictionary when he came home from the hospital and crossed out the word impossible.

Now he has a collection of dictionaries, where he highlights favorite words or words that remind him of himself. Just try to beat him at scrabble.

"I wanted to prove to Aaron that he could have a perfect life," Ann said.

"I have one," Aaron replied. "I have you as my mom."

Jen Rini can be reached at (302)324-2386 or jrini@delawareonline.com. Follow @JenRini on Twitter.

CAREGIVING INFO

Go to www.dhss.delaware.gov/dsaapd/resource.html (<http://www.dhss.delaware.gov/dsaapd/resource.html>), www.caregiving.org/coalitions/annual-conference/ (<http://www.caregiving.org/coalitions/annual-conference/>) and www.delawarefamilytofamily.org/ (<http://www.delawarefamilytofamily.org/>) for resources on caregiving and where to find help.

FAST FACTS

Family caregivers in Delaware provided 114 million hours of care to loved ones in 2013, estimated at \$1.58 billion.

Nearly half of Delawareans over age 35 provide unpaid care to a loved one.

Read or Share this story: <http://delonline.us/1RydnEi>



	NOTICE	Number 915.002
EEOC		Date 5/23/07

SUBJECT: Enforcement Guidance: Unlawful Disparate Treatment of Workers with Caregiving Responsibilities

PURPOSE: This document provides guidance regarding unlawful disparate treatment under the federal EEO laws of workers with caregiving responsibilities .

EFFECTIVE DATE: Upon receipt.

EXPIRATION DATE: As an exception to EEOC Order 205.001, Appendix B, Attachment, § a(5), this Notice will remain in effect until rescinded or superseded.

ORIGINATOR: Title VII/EPA/ADEA Division, Office of Legal Counsel

SUBJECT MATTER: File after Section 615 of Volume II of the Compliance Manual.

Naomi C. Earp
Chair

See Also:

- [Employer Best Practices for Workers with Caregiving Responsibilities](#)
- [Questions and Answers about EEOC's Enforcement Guidance on Unlawful Disparate Treatment of Workers with Caregiving Responsibilities](#)

ENFORCEMENT GUIDANCE: UNLAWFUL DISPARATE TREATMENT OF WORKERS WITH CAREGIVING RESPONSIBILITIES

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Notice Concerning The Americans With Disabilities Act Amendments Act Of 2008

The Americans with Disabilities Act (ADA) Amendments Act of 2008 was signed into law on September 25, 2008 and becomes effective January 1, 2009. Because this law makes several significant changes, including changes to the definition of the term "disability," the EEOC will be evaluating the impact of these changes on this document and other publications. See the [list of specific changes to the ADA](#) made by the ADA Amendments Act.

Although the federal EEO laws do not prohibit discrimination against caregivers per se, there are circumstances in which discrimination against caregivers might constitute unlawful disparate treatment. The purpose of this document is to assist investigators, employees, and employers in assessing whether a particular employment decision affecting a caregiver might unlawfully discriminate on the basis of prohibited characteristics under Title VII of the Civil Rights Act of 1964 or the Americans with Disabilities Act of 1990. This document is not intended to create a new protected category but rather to illustrate circumstances in which stereotyping or other forms of disparate treatment may violate Title VII or the prohibition under the ADA against discrimination based on a worker's association with an individual with a disability. An employer may also have specific obligations towards caregivers under other federal statutes, such as the Family and Medical Leave Act, or under state or local laws.¹

I. BACKGROUND AND INTRODUCTION

A. Caregiving Responsibilities of Workers

The prohibition against sex discrimination under Title VII has made it easier for women to enter the labor force. Since Congress enacted Title VII, the proportion of women who work outside the home has significantly increased,² and women now comprise nearly half of the U.S. labor force.³ The rise has been most dramatic for mothers of young children, who are almost twice as likely to be employed today as were their counterparts 30 years ago.⁴ The total amount of time that couples with children spend working also has increased.⁵ Income from women's employment is important to the economic security of many families, particularly among lower-paid workers, and accounts for over one-third of the income in families where both parents work.⁶ Despite these changes, women continue to be most families' primary caregivers.⁷

Of course, workers' caregiving responsibilities are not limited to childcare, and include many other forms of caregiving. An increasing proportion of caregiving goes to the elderly, and this trend will likely continue as the Baby Boomer population ages.⁸ As with childcare, women are primarily responsible for caring for society's elderly, including care of parents, in-laws, and spouses.⁹ Unlike childcare, however, eldercare responsibilities generally increase over time as the person cared for ages, and eldercare can be much less predictable than childcare because of health crises that typically arise.¹⁰ As eldercare becomes more common, workers in the "sandwich generation," those between the ages of 30 and 60, are more likely to face work responsibilities alongside both childcare and eldercare responsibilities.¹¹

Caring for individuals with disabilities – including care of adult children, spouses, or parents – is also a common responsibility of workers.¹² According to the most recent U.S. census, nearly a third of families have at least one family member with a disability, and about one in ten families with children under 18 years of age includes a child with a disability.¹³ Most men and women who provide care to relatives or other individuals with a disability are employed.¹⁴

While caregiving responsibilities disproportionately affect working women generally, their effects may be even more pronounced among some women of color, particularly African American women,¹⁵ who have a long history of working outside the home.¹⁶ African American mothers with young children are more likely to be employed than other women raising young children,¹⁷ and both African American and Hispanic women are more likely to be raising children in a single-parent household than are White or Asian American women.¹⁸ Women of color also may devote more time to caring for extended family members, including both grandchildren¹⁹ and elderly relatives,²⁰ than do their White counterparts.

Although women are still responsible for a disproportionate share of family caregiving, men's role has increased. Between 1965 and 2003, the amount of time that men spent on childcare nearly tripled, and men spent more than twice as long performing household chores in 2003 as they did in 1965.²¹ Working mothers are also increasingly relying on fathers as primary childcare providers.²²

B. Work-Family Conflicts

As more mothers have entered the labor force, families have increasingly faced conflicts between work and family responsibilities, sometimes resulting in a "maternal wall" that limits the employment opportunities of workers with caregiving responsibilities.²³ These conflicts are perhaps felt most profoundly by lower-paid workers,²⁴ who are disproportionately people of color.²⁵ Unable to afford to hire a childcare provider, many couples "tag team" by working opposite shifts and taking turns caring for their children. In comparison to professionals, lower-paid workers tend to have much less control over their schedules and are more likely to face inflexible employer policies, such as mandatory overtime.²⁶ Family crises can sometimes lead to discipline or even discharge when a worker violates an employer policy in order to address caregiving responsibilities.²⁷

The impact of work-family conflicts also extends to professional workers, contributing to the maternal wall or "glass ceiling" that prevents many women from advancing in their careers. As a recent EEOC report reflects, even though women constitute about half of the labor force, they are a much smaller proportion of managers and officials.²⁸ The disparity is greatest at the highest levels in the business world, with women accounting for only 1.4% of Fortune 500 CEOs.²⁹ Thus, one of the recommendations made by the federal Glass Ceiling Commission in 1995 was for organizations to adopt policies that allow workers to balance work and family responsibilities throughout their careers.³⁰

Individuals with caregiving responsibilities also may encounter the maternal wall through employer stereotyping. Writing for the Supreme Court in 2003, Chief Justice Rehnquist noted that "the faultline between work and family [is] precisely where sex-based overgeneralization has been and remains strongest."³¹ Sex-based stereotyping about caregiving responsibilities is not limited to childcare and includes other forms of caregiving, such as care of a sick parent or spouse.³² Thus, women with caregiving responsibilities may be perceived as more committed to caregiving than to their jobs and as less competent than other workers, regardless of how their caregiving responsibilities actually impact their work.³³ Male caregivers may face the mirror image stereotype: that men are poorly suited to caregiving. As a result, men may be denied parental leave or other benefits routinely afforded their female counterparts.³⁴ Racial and ethnic stereotypes may further limit employment opportunities for people of color.³⁵

Employment decisions based on such stereotypes violate the federal antidiscrimination statutes,³⁶ even when an employer acts upon such stereotypes unconsciously or reflexively.³⁷ As the Supreme Court has explained, "[W]e are beyond the day when an employer could evaluate employees by assuming or insisting that they match the stereotype associated with their group."³⁸ Thus, for example, employment decisions based on stereotypes about working mothers are unlawful because "the antidiscrimination laws entitle individuals to be evaluated as individuals rather than as members of groups having certain average characteristics."³⁹

Although some employment decisions that adversely affect caregivers may not constitute unlawful discrimination based on sex or another protected characteristic, the Commission strongly encourages employers to adopt best practices to make it easier for all workers, whether male or female, to balance work and personal responsibilities. There is substantial evidence that workplace flexibility enhances employee satisfaction and job performance.⁴⁰ Thus, employers can benefit by adopting such flexible workplace policies⁴¹ by, for example, saving millions of dollars in retention costs.⁴²

II. UNLAWFUL DISPARATE TREATMENT OF CAREGIVERS

This section illustrates various circumstances under which discrimination against a worker with caregiving responsibilities constitutes unlawful disparate treatment under Title VII or the ADA. Part A discusses sex-based disparate treatment of female caregivers, focusing on sex-based stereotypes. Part B discusses stereotyping and other disparate treatment of pregnant workers. Part C discusses sex-based disparate treatment of male caregivers, such as the denial of childcare leave that is available to female workers. Part D discusses disparate treatment of women of color who have caregiving responsibilities. Part E discusses disparate treatment of a worker with caregiving responsibilities for an individual with a disability, such as a child or a parent. Finally, part F discusses harassment resulting in a hostile work environment for a worker with caregiving responsibilities.

A. Sex-based Disparate Treatment of Female Caregivers

1. Analysis of Evidence

Intentional sex discrimination against workers with caregiving responsibilities can be proven using any of the types of evidence used in other sex discrimination cases. As with any other charge, investigators faced with a charge alleging sex-based disparate treatment of female caregivers should examine the totality of the evidence to determine whether the particular challenged action was unlawfully discriminatory. All evidence should be examined in context. The presence or absence of any particular kind of evidence is not dispositive. For example, while comparative evidence is often useful, it is not necessary to establish a violation.⁴³ There may be evidence of comments by officials about the reliability of working mothers or evidence that, despite the absence of a decline in work performance, women were subjected to less favorable treatment after they had a baby. It is essential that there be evidence that the adverse action taken against the caregiver was based on sex.

Relevant evidence in charges alleging disparate treatment of female caregivers may include, but is not limited to, any of the following:

- Whether the respondent asked female applicants, but not male applicants, whether they were married or had young children, or about their childcare and other caregiving responsibilities;
- Whether decisionmakers or other officials made stereotypical or derogatory comments about pregnant workers or about working mothers or other female caregivers;⁴⁴
- Whether the respondent began subjecting the charging party or other women to less favorable treatment soon after it became aware that they were pregnant;⁴⁵
- Whether, despite the absence of a decline in work performance, the respondent began subjecting the charging party or other women to less favorable treatment after they assumed caregiving responsibilities;
- Whether female workers without children or other caregiving responsibilities received more favorable treatment than female caregivers based upon stereotypes of mothers or other female caregivers;
- Whether the respondent steered or assigned women with caregiving responsibilities to less prestigious or lower-paid positions;
- Whether male workers with caregiving responsibilities received more favorable treatment than female workers;⁴⁶
- Whether statistical evidence shows disparate treatment against pregnant workers or female caregivers;⁴⁷
- Whether respondent deviated from workplace policy when it took the challenged action;
- Whether the respondent's asserted reason for the challenged action is credible.⁴⁸

2. Unlawful Disparate Treatment of Female Caregivers as Compared with Male Caregivers

Employment decisions that discriminate against workers with caregiving responsibilities are prohibited by Title VII if they are based on sex or another protected characteristic, regardless of whether the employer discriminates more broadly against all members of the protected class. For example, sex discrimination against working mothers is prohibited by Title VII even if the employer does not discriminate against childless women.⁴⁹

EXAMPLE 1 UNLAWFUL DISCRIMINATION AGAINST WOMEN WITH YOUNG CHILDREN

Charmaine, a mother of two preschool-age children, files an EEOC charge alleging sex discrimination after she is rejected for an opening in her employer's executive training program. The employer asserts that it rejected Charmaine because candidates who were selected had better performance appraisals or more managerial experience and because she is not "executive material." The employer also contends that the fact that half of the selectees were women shows that her rejection could not have been because of sex. However, the investigation reveals that Charmaine had more managerial experience or better performance appraisals than several selectees and was better qualified than some selectees, including both men and women, as weighted pursuant to the employer's written selection policy. In addition, while the employer selected both men and women for the program, the only selectees with preschool age children were men. Under the circumstances, the investigator determines that Charmaine was subjected to discrimination based on her sex.

Title VII does not prohibit discrimination based solely on parental or other caregiver status, so an employer does not generally violate Title VII's disparate treatment proscription if, for example, it treats working mothers and working fathers in a similar unfavorable (or favorable) manner as compared to childless workers.

3. Unlawful Gender Role Stereotyping of Working Women

Although women actually do assume the bulk of caretaking responsibilities in most families and many women do curtail their work responsibilities when they become caregivers, Title VII does not permit employers to treat female workers less favorably merely on the gender-based assumption that a particular female worker will assume caretaking responsibilities or that a female worker's caretaking responsibilities will interfere with her work performance.⁵⁰ Because

stereotypes that female caregivers should not, will not, or cannot be committed to their jobs are sex-based, employment decisions based on such stereotypes violate Title VII.⁵¹

Gender-based Assumptions About Future Caregiving Responsibilities

Relying on stereotypes of traditional gender roles and the division of domestic and workplace responsibilities, some employers may assume that childcare responsibilities will make female employees less dependable than male employees, even if a female worker is not pregnant and has not suggested that she will become pregnant.⁵² Fear of such stereotyping may even prompt married female job applicants to remove their wedding rings before going into an interview.⁵³

EXAMPLE 2 UNLAWFUL STEREOTYPING DURING HIRING PROCESS

Patricia, a recent business school graduate, was interviewed for a position as a marketing assistant for a public relations firm. At the interview, Bob, the manager of the department with the vacancy being filled, noticed Patricia's wedding ring and asked, "How many kids do you have?" Patricia told Bob that she had no children yet but that she planned to once she and her husband had gotten their careers underway. Bob explained that the duties of a marketing assistant are very demanding, and rather than discuss Patricia's qualifications, he asked how she would balance work and childcare responsibilities when the need arose. Patricia explained that she would share childcare responsibilities with her husband, but Bob responded that men are not reliable caregivers. Bob later told his secretary that he was concerned about hiring a young married woman – he thought she might have kids, and he didn't believe that being a mother was "compatible with a fast-paced business environment." A week after the interview, Patricia was notified that she was not hired.

Believing that she was well qualified and that the interviewer's questions reflected gender bias, Patricia filed a sex discrimination charge with the EEOC. The investigator discovered that the employer reposted the position after rejecting Patricia. The employer said that it reposted the position because it was not satisfied with the experience level of the applicants in the first round. However, the investigation showed that Patricia easily met the requirements for the position and had as much experience as some other individuals recently hired as marketing assistants. Under the circumstances, the investigator determines that the respondent rejected Patricia from the first round of hiring because of sex-based stereotypes in violation of Title VII.

Mixed-motives Cases

An employer violates Title VII if the charging party's sex was a motivating factor in the challenged employment decision, regardless of whether the employer was also motivated by legitimate business reasons.⁵⁴ However, when an employer shows that it would have taken the same action even absent the discriminatory motive, the complaining employee will not be entitled to reinstatement, back pay, or damages.⁵⁵

EXAMPLE 3 DECISION MOTIVATED BY BOTH UNLAWFUL STEREOTYPING AND LEGITIMATE BUSINESS REASON

Same facts as above except that the employer did not repost the position but rather hired Tom from the same round of candidates that Patricia was in. In addition, the record showed that other than Tom's greater experience, Tom and Patricia had similar qualifications but that the employer consistently used relevant experience as a tiebreaking factor in filling marketing positions. The investigator determines that the employer has violated Title VII because sex was a motivating factor in the employer's decision not to hire Patricia as evidenced by Bob's focus on caregiving responsibilities, rather than qualifications, when he interviewed Patricia and other female candidates. However, the employer would have selected Tom, even absent the discriminatory motive, based on his greater experience. Thus, Patricia may be entitled to attorney's fees and/or injunctive relief, but is not entitled to reinstatement, back pay, or compensatory or punitive damages.

Assumptions About the Work Performance of Female Caregivers

The effects of stereotypes may be compounded after female employees become pregnant or actually begin assuming caregiving responsibilities. For example, employers may make the stereotypical assumptions that women with young children will (or should) not work long hours and that new mothers are less committed to their jobs than they were before they had children.⁵⁶ Relying on such stereotypes, some employers may deny female caregivers opportunities based on assumptions about how they might balance work and family responsibilities. Employers may further stereotype female caregivers who adopt part-time or flexible work schedules as "homemakers" who are less committed to the workplace than their full-time colleagues.⁵⁷ Adverse employment decisions based on such sex-based assumptions or speculation, rather than on the specific work performance of a particular employee, violate Title VII.

EXAMPLE 4 UNLAWFUL SEX-BASED ASSUMPTIONS ABOUT WORK PERFORMANCE

Anjali, a police detective, had received glowing performance reviews during her first four years with the City's police department and was assumed to be on a fast track for promotion. However, after she returned from leave to adopt a child during her fifth year with the department, her supervisor frequently asked how Anjali was going to manage to stay on top of her case load while caring for an infant. Although Anjali continued to work the same hours and close as many cases as she had before the adoption, her supervisor pointed out that none of her superiors were mothers, and he removed her from her high-profile cases, assigning her smaller, more routine cases normally handled by inexperienced detectives. The City has

violated Title VII by treating Anjuli less favorably because of gender-based stereotypes about working mothers.

EXAMPLE 5
UNLAWFUL STEREOTYPING BASED ON PARTICIPATION IN FLEXIBLE WORK ARRANGEMENT

Emily, an assistant professor of mathematics at the University for the past seven years, files a charge alleging that she was denied tenure based on her sex. Emily applied for tenure after she returned from six months of leave to care for her father. The University's flexible work program allowed employees to take leave for a year without penalty. Before taking leave, Emily had always received excellent performance reviews and had published three highly regarded books in her field. After returning from leave, however, Emily believed she was held to a higher standard of review than her colleagues who were not caregivers or had not taken advantage of the leave policies, as reflected in the lower performance evaluations that she received from the Dean of her department after returning from leave. Emily applied for tenure, but the promotion was denied by the Dean, who had a history of criticizing female faculty members who took time off from their careers and was heard commenting that "she's just like the other women who think they can come and go as they please to take care of their families."

While the University acknowledges that Emily was eligible for tenure, it asserts that it denied Emily tenure because of a decline in her performance. The investigation reveals, however, that Emily's post-leave work output and classroom evaluations were comparable to her work performance before taking leave. In addition, The University does not identify any specific deficiencies in Emily's performance that warranted the decline in its evaluation of her work. Under the circumstances, the investigator determines that Emily was denied tenure because of her sex.

Employment decisions that are based on an employee's actual work performance, rather than assumptions or stereotypes, do not generally violate Title VII, even if an employee's unsatisfactory work performance is attributable to caregiving responsibilities.

EXAMPLE 6
EMPLOYMENT DECISION LAWFULLY BASED ON ACTUAL WORK PERFORMANCE

After Carla, an associate in a law firm, returned from maternity leave, she began missing work frequently because of her difficulty in obtaining childcare and was unable to meet several important deadlines. As a result, the firm lost a big client, and Carla was given a written warning about her performance. Carla's continued childcare difficulties resulted in her missing further deadlines for several important projects. Two months after Carla was given the written warning, the firm transferred her to another department, where she would be excluded from most high-profile cases but would perform work that has fewer time constraints. Carla filed a charge alleging sex discrimination. The investigation revealed that Carla was treated comparably to other employees, both male and female, who had missed deadlines on high-profile projects or otherwise performed unsatisfactorily and had failed to improve within a reasonable period of time. Therefore, the employer did not violate Title VII by transferring Carla.

"Benevolent" Stereotyping

Adverse employment decisions based on gender stereotypes are sometimes well-intentioned and perceived by the employer as being in the employee's best interest.⁵⁸ For example, an employer might assume that a working mother would not want to relocate to another city, even if it would mean a promotion.⁵⁹ Of course, adverse actions that are based on sex stereotyping violate Title VII, even if the employer is not acting out of hostility.⁶⁰

EXAMPLE 7
STEREOTYPING UNLAWFUL EVEN IF FOR BENEVOLENT REASONS

Rhonda, a CPA at a mid-size accounting firm, mentioned to her boss that she had become the guardian of her niece and nephew and they were coming to live with her, so she would need a few days off to help them settle in. Rhonda's boss expressed concern that Rhonda would be unable to balance her new family responsibilities with her demanding career, and was worried that Rhonda would suffer from stress and exhaustion. Two weeks later, he moved her from her lead position on three of the firm's biggest accounts and assigned her to supporting roles handling several smaller accounts. In doing so, the boss told Rhonda that he was transferring her so that she "would have more time to spend with her new family," despite the fact that Rhonda had asked for no additional leave and had been completing her work in a timely and satisfactory manner. At the end of the year, Rhonda, for the first time in her 7-year stint at the firm, is denied a pay raise, even though many other workers did receive raises. When she asks for an explanation, she is told that she needs to be available to work on bigger accounts if she wants to receive raises. Here, the employer has engaged in unlawful sex discrimination by taking an adverse action against a female employee based on stereotypical assumptions about women with caregiving responsibilities, even if the employer believed that it was acting in the employee's best interest.

In some circumstances, an employer will take an action that unlawfully imposes on a female worker the employer's own stereotypical views of how the worker *should* act even though the employer is aware that the worker objects. Thus, if a supervisor believes that mothers should not work full time, he or she might refuse to consider a working mother for a promotion that would involve a substantial increase in hours, even if that worker has made it clear that she would accept the promotion if offered.

EXAMPLE 8
DENIAL OF PROMOTION BASED ON STEREOTYPE OF HOW MOTHERS SHOULD ACT

Sun, a mid-level manager in a data services company, applied for a promotion to a newly created upper-level management position. At the interview for the promotion, the selecting official, Charlie, who had never met Sun before, asked her about her childcare responsibilities. Sun explained that she had two teenage

children and that she commuted every week between her home in New York and the employer's main office in Northern Virginia. Charlie asked Sun how her husband handled the fact that she was "away from home so much, not caring for the family except on weekends." Sun explained that her husband and their children "helped each other" to function as "a successful family," but Charlie responded that he had "a very difficult time understanding why any man would allow his wife to live away from home during the work week." After Sun is denied the promotion, she files an EEOC charge alleging sex discrimination. According to the employer, it considered Sun and one other candidate for the promotion, and, although they were both well qualified, it did not select Sun because it felt that it was unfair to Sun's children for their mother to work so far from home. Under the circumstances, the investigator determines that the employer denied Sun the promotion because of unlawful sex discrimination, basing its decision in particular on stereotypes that women with children should not live away from home during the week.⁶¹

4. Effects of Stereotyping on Subjective Assessments of Work Performance

In addition to leading to assumptions about how female employees might balance work and caregiving responsibilities, gender stereotypes of caregivers may more broadly affect perceptions of a worker's general competence.⁶² Once female workers have children, they may be perceived by employers as being less capable and skilled than their childless female counterparts or their male counterparts, regardless of whether the male employees have children.⁶³ These gender-based stereotypes may even place some working mothers in a "double bind," in which they are simultaneously viewed by their employers as "bad mothers" for investing time and resources into their careers and "bad workers" for devoting time and attention to their families.⁶⁴ The double bind may be particularly acute for mothers or other female caregivers who work part time. Colleagues may view part-time working mothers as uncommitted to work while viewing full-time working mothers as inattentive mothers.⁶⁵ Men who work part time may encounter different, though equally harmful, stereotypes.⁶⁶

Investigators should be aware that it may be more difficult to recognize sex stereotyping when it affects an employer's evaluation of a worker's general competence than when it leads to assumptions about how a worker will balance work and caregiving responsibilities. Such stereotyping can be based on unconscious bias, particularly where officials engage in subjective decisionmaking. As with other forms of gender stereotyping, comparative evidence showing more favorable treatment of male caregivers than female caregivers is helpful but not necessary to establish a violation.⁶⁷ Investigators should be particularly attentive, for example, to evidence of the following:

- Changes in an employer's assessment of a worker's performance that are not linked to changes in the worker's actual performance and that arise after the worker becomes pregnant or assumes caregiving responsibilities;
- Subjective assessments that are not supported by specific objective criteria; and
- Changes in assignments or duties that are not readily explained by nondiscriminatory reasons.

EXAMPLE 9 EFFECTS OF STEREOTYPING ON EMPLOYER'S PERCEPTION OF EMPLOYEE

Barbara, a highly successful marketing executive at a large public relations firm, recently became the primary caregiver for her two young grandchildren. Twice a month, Barbara and her marketing colleagues are expected to attend a 9 a.m. corporate sales meeting. Last month, Barbara arrived a few minutes late to the meeting. Barbara did not think her tardiness was noteworthy since one of her colleagues, Jim, regularly arrived late to the meetings. However, after her late arrival, Barbara's boss, Susan, severely criticized her for the incident and informed her that she needed to start keeping a daily log of her activities.

The next month, Susan announced that one of the firm's marketing executives would be promoted to the position of Vice President. After Susan selected Jim, Barbara filed a charge alleging that she was denied the promotion because of her sex. According to Susan, she selected Jim because she believed that he was more "dependable, reliable, and committed to his work" than other candidates. Susan explained to the investigator that she thought as highly of Barbara's work as she did of Jim's, but she decided not to promote a worker who arrived late to sales meetings, even if it was because of childcare responsibilities. Other employees stated that they could only remember Barbara's being late on one occasion, but that Jim had been late on numerous occasions. When asked about this, Susan admitted that she might have forgotten about the times when Jim was late, but still considered Jim to be much more dependable. The investigator asks Susan for more specifics, but Susan merely responds that her opinion was based on many years of experience working with both Barbara and Jim. Under the circumstances, the investigator concludes that Susan denied Barbara the promotion because of her sex.

EXAMPLE 10 SUBJECTIVE DECISIONMAKING BASED ON NONDISCRIMINATORY FACTORS

Simone, the mother of two elementary-school-age children, files an EEOC charge alleging sex discrimination after she is terminated from her position as a reporter with a medium-size newspaper. The employer asserts that it laid Simone off as part of a reduction in force in response to decreased revenue. The employer states that Simone's supervisor, Alex, compared Simone with two other reporters in the same department to determine whom to lay off. According to Alex, he considered Jocelyn (an older woman with two grown children) to be a superior worker to Simone because Jocelyn's work needed less editing and supervision and she had the most experience of anyone in the department. Alex said he also favored Louis (a young male worker with no children) over Simone because Louis had shown exceptional initiative and creativity by writing several stories that had received national publicity and by creating a new feature to increase youth readership and advertising revenue. Alex said that he considered Simone's work satisfactory, but that she lacked the unique talents that Jocelyn and Louis brought to the department. Because the investigation does not reveal that the reasons provided by Alex are a pretext for sex discrimination, the investigator does not find that Simone was subjected to sex discrimination.

B. Pregnancy Discrimination

Employers can also violate Title VII by making assumptions about pregnancy, such as assumptions about the commitment of pregnant workers or their ability to perform certain physical tasks.⁶⁸ As the Supreme Court has noted, "[W]omen as capable of doing their jobs as their male counterparts may not be forced to choose between having a child and having a job."⁶⁹ Title VII's prohibition against sex discrimination includes a prohibition against employment decisions based on pregnancy, even where an employer does not discriminate against women generally.⁷⁰ As with other sex-based stereotypes, Title VII prohibits an employer from basing an adverse employment decision on stereotypical assumptions about the effect of pregnancy on an employee's job performance, regardless of whether the employer is acting out of hostility or a belief that it is acting in the employee's best interest.

Because Title VII prohibits discrimination based on pregnancy, employers should not make pregnancy-related inquiries. The EEOC will generally regard a pregnancy-related inquiry as evidence of pregnancy discrimination where the employer subsequently makes an unfavorable job decision affecting a pregnant worker.⁷¹ Employers should be aware that pregnancy testing also implicates the ADA, which restricts employers' use of medical examinations.⁷² Given the potential Title VII and ADA implications, the Commission strongly discourages employers from making pregnancy-related inquiries or conducting pregnancy tests.

An employer also may not treat a pregnant worker who is temporarily unable to perform some of her job duties because of pregnancy less favorably than workers whose job performance is similarly restricted because of conditions other than pregnancy. For example, if an employer provides up to eight weeks of paid leave for temporary medical conditions, then the employer must provide up to eight weeks of paid leave for pregnancy or related medical conditions.⁷³

For more information on pregnancy discrimination under Title VII, see "Questions and Answers on the Pregnancy Discrimination Act," 29 C.F.R. Part 1604 Appendix (1978).

EXAMPLE 11 UNLAWFUL STEREOTYPING BASED ON PREGNANCY

Anna, a records administrator for a health maintenance organization, was five months pregnant when she missed two days of work due to a pregnancy-related illness. Upon her return to work, Anna's supervisor, Tom, called her into his office and told her that "her body was trying to tell her something" and that "her attendance was becoming a serious problem." Anna reminded him that she had only missed two days and that her doctor had found no continuing complications related to her brief illness. However, Tom responded, "Well, now that you're pregnant, you will probably miss a lot of work, and we need someone who will be dependable." Tom placed Anna on an unpaid leave of absence, telling her that she would be able to return to work after she had delivered her baby and had time to recuperate and that "not working [was] the best thing for [her] right now." In response to Anna's EEOC charge alleging pregnancy discrimination, the employer states that it placed Anna on leave because of poor attendance. The investigation reveals, however, that Anna had an excellent attendance record before she was placed on leave. In the prior year, she had missed only three days of work because of illness, including two days for her pregnancy-related illness and one day when she was ill before she became pregnant. The investigator concludes that the employer subjected Anna to impermissible sex discrimination under Title VII by basing its action on a stereotypical assumption that pregnant women are poor attendees and that Anna would be unable to meet the requirements of the job.⁷⁴

EXAMPLE 12 UNLAWFUL REFUSAL TO MODIFY DUTIES

Ingrid, a pregnant machine operator at a bottling company, is told by her doctor to temporarily refrain from lifting more than 20 pounds. As part of her job as a machine operator, Ingrid is required to carry certain materials weighing more than 20 pounds to and from her machine several times each day. She asks her supervisor if she can be temporarily relieved of this function. The supervisor refuses, stating that he can't reassign her job duties but can transfer her temporarily to another lower-paying position for the duration of the lifting restriction. Ingrid reluctantly accepts the transfer but also files an EEOC charge alleging sex discrimination. The investigation reveals that in the previous six months, the employer had reassigned the lifting duties of three other machine operators, including a man who injured his arm in an automobile accident and a woman who had undergone surgery to treat a hernia. Under the circumstances, the investigator determines that the employer subjected Ingrid to discrimination based on sex (i.e., pregnancy).

C. *Discrimination Against Male Caregivers*⁷⁵

The Supreme Court has observed that gender-based stereotypes also influence how male workers are perceived: "Stereotypes about women's domestic roles are reinforced by parallel stereotypes presuming a lack of domestic responsibilities for men. These mutually reinforcing stereotypes created a self-fulfilling cycle of discrimination."⁷⁶ Stereotypes of men as "bread winners" can further lead to the perception that a man who works part time is not a good father, even if he does so to care for his children.⁷⁷ Thus, while working women have generally borne the brunt of gender-based stereotyping, unlawful assumptions about working fathers and other male caregivers have sometimes led employers to deny male employees opportunities that have been provided to working women or to subject men who are primary caregivers to harassment or other disparate treatment.⁷⁸ For example, some employers have denied male employees' requests for leave for childcare purposes even while granting female employees' requests. For more information on how to determine whether an employee has been subjected to unlawful disparate treatment, see the discussion at § II.A.1, above, "Sex-based Disparate Treatment of Female Caregivers – Analysis of Evidence."

Significantly, while employers are permitted by Title VII to provide women with leave specifically for the period that they are incapacitated because of pregnancy, childbirth, and related medical conditions, employers may not treat either sex more favorably with respect to other kinds of leave, such as leave for childcare purposes.⁷⁹ To avoid a potential Title VII violation, employers should carefully distinguish between pregnancy-related leave and other forms of leave, ensuring that any leave specifically provided to women alone is limited to the period that women are incapacitated by pregnancy and childbirth.⁸⁰

EXAMPLE 13
EMPLOYER UNLAWFULLY DENIED BENEFIT TO MALE WORKER BECAUSE OF GENDER-BASED STEREOTYPE

Eric, an elementary school teacher, requests unpaid leave for the upcoming school year for the purpose of caring for his newborn son. Although the school has a collective bargaining agreement that allows for up to one year of unpaid leave for various personal reasons, including to care for a newborn, the Personnel Director denies the request. When Eric points out that women have been granted childcare leave, the Director says, "That's different. We have to give childcare leave to women." He suggests that Eric instead request unpaid emergency leave, though that is limited to 90 days. This is a violation of Title VII because the employer is denying male employees a type of leave, unrelated to pregnancy, that it is granting to female employees.

EXAMPLE 14
EMPLOYER UNLAWFULLY DENIED PART-TIME POSITION TO MALE WORKER BECAUSE OF SEX

Tyler, a service technician for a communications company, requests reassignment to a part-time position so that he can help care for his two-year-old daughter when his wife returns to work. Tyler's supervisor, however, rejects the request, saying that the department has only one open slot for a part-time technician, and he has reserved it in case it is needed by a female technician. Tyler's supervisor says that Tyler can have a part-time position should another one open up. After two months, no additional slots have opened up, and Tyler files an EEOC charge alleging sex discrimination. Under the circumstances the employer has discriminated against Tyler based on sex by denying him a part-time position.

D. Discrimination Against Women of Color

In addition to sex discrimination, race or national origin discrimination may be a further employment barrier faced by women of color who are caregivers. For example, a Latina working mother might be subjected to discrimination by her supervisor based on his stereotypical notions about working mothers or pregnant workers, as well as his hostility toward Latinos generally. Women of color also may be subjected to intersectional discrimination that is specifically directed toward women of a particular race or ethnicity, rather than toward all women, resulting, for example, in less favorable treatment of an African American working mother than her White counterpart.⁸¹

EXAMPLE 15
UNLAWFUL DENIAL OF COMPENSATORY TIME BASED ON RACE

Margaret, an African American employee in the City's Parks and Recreation Department, files an EEOC charge alleging that she was denied the opportunity to use compensatory time because of her race. She asked her supervisor, Sarah, for the opportunity to use compensatory time so she could occasionally be absent during regular work hours to address personal responsibilities, such as caring for her children when she does not have a sitter. Sarah rejected the request, explaining that Margaret's position has set hours and that any absences must be under the official leave policy. The investigation reveals that while the City does not have an official compensatory time policy, several White employees in Margaret's position have been allowed to use compensatory time for childcare purposes. When asked about this discrepancy, Sarah merely responds that those employees' situations were "different." In addition, the investigation reveals that while White employees have been allowed to use compensatory time, no African Americans have been allowed to do so. Under the circumstances, the investigator determines that Margaret was unlawfully denied the opportunity to use compensatory time based on her race.

EXAMPLE 16
UNLAWFUL HARASSMENT AND REASSIGNMENT BASED ON SEX AND NATIONAL ORIGIN

Christina, a Mexican-American, filed an EEOC charge alleging that she was subjected to discrimination based on national origin and pregnancy. Christina had worked as a server waiting tables at a large chain restaurant until she was reassigned to a kitchen position when she was four months pregnant. One of Christina's supervisors has regularly made comments in the workplace about how Mexicans are entering the country illegally and taking jobs from other people. After Christina becomes pregnant, he began directing the comments at Christina, telling her that Mexican families are too large and that it is not fair for Mexicans to come to the United States and "take over" and use up tax dollars. When he reassigned Christina, he explained to her that he thought customers' appetites would be spoiled if they had their food brought to them by someone who was pregnant. Under these circumstances, the evidence shows that Christina was subjected to discrimination based on both sex (pregnancy) and national origin.

E. Unlawful Caregiver Stereotyping Under the Americans with Disabilities Act

In addition to prohibiting discrimination against a qualified worker because of his or her own disability, the Americans with Disabilities Act (ADA) prohibits discrimination because of the disability of an individual with whom the worker has a relationship or association, such as a child, spouse, or parent.⁸² Under this provision, an employer may not treat a worker less favorably based on stereotypical assumptions about the worker's ability to perform job duties satisfactorily while also providing care to a relative or other individual with a disability. For example, an employer may not refuse to hire a job applicant whose wife has a disability because the employer assumes that the applicant would have to use frequent leave and arrive late due to his responsibility to care for his wife.⁸³ For more information, see EEOC's *Questions and Answers About the Association Provision of the ADA* at https://www.eeoc.gov/facts/association_ada.html.

EXAMPLE 17
UNLAWFUL STEREOTYPING BASED ON ASSOCIATION WITH AN INDIVIDUAL WITH A DISABILITY

An employer is interviewing applicants for a computer programmer position. The employer determines that one of the applicants, Arnold, is the best qualified, but is reluctant to hire him because he disclosed during the interview that he is a divorced father and has sole custody of his son, who has a disability. Because the employer

concludes that Arnold's caregiving responsibilities for a person with a disability may have a negative effect on his attendance and work performance, it decides to offer the position to the second best qualified candidate, Fred, and encourages Arnold to apply for any future openings if his caregiving responsibilities change. Under the circumstances, the employer has violated the ADA by refusing to hire Arnold because of his association with an individual with a disability.

F. Hostile Work Environment

Employers may be liable if workers with caregiving responsibilities are subjected to offensive comments or other harassment because of race, sex (including pregnancy), association with an individual with a disability,⁸⁵ or another protected characteristic and the conduct is sufficiently severe or pervasive to create a hostile work environment.⁸⁵ The same legal standards that apply to other forms of harassment prohibited by the EEO statutes also apply to unlawful harassment directed at caregivers or pregnant workers.

Employers should take steps to prevent harassment directed at caregivers or pregnant workers from occurring in the workplace and to promptly correct any such conduct that does occur. In turn, employees who are subjected to such harassment should follow the employer's harassment complaint process or otherwise notify the employer about the conduct, so that the employer can investigate the matter and take appropriate action. For more information on harassment claims generally, see *EEOC Policy Guidance on Current Issues of Sexual Harassment* (Mar. 19, 1990) at <https://www.eeoc.gov/policy/docs/currentissues.html>, and Enforcement Guidance: Vicarious Employer Liability for Unlawful Harassment by Supervisors (June 19, 1999) at <https://www.eeoc.gov/policy/docs/harassment.html>.

EXAMPLE 18 HOSTILE WORK ENVIRONMENT BASED ON STEREOTYPES OF MOTHERS

After Yael, a supervisor at a construction site, returned to work from maternity leave, she asked her supervisor, Rochelle, for permission to use her lunch break to breastfeed her child at the child's day care center. Rochelle agreed, but added, "Now that you're a mother, you won't have the same dedication to the job. That's why I never had any kids! Maybe you should rethink being a supervisor." She also began monitoring Yael's time, tracking when Yael left and returned from her lunch break and admonishing her if she was late, even only a few minutes. Other employees who left the site during lunch were not similarly monitored. Rochelle warned Yael that if she had another child, she could "kiss her career goodbye," and that it was impossible for any woman to be a good mother and a good supervisor at the same time. Yael is very upset by her supervisor's conduct and reports it to a higher-level manager. However, the employer refuses to take any action, stating that Yael is merely complaining about a "personality conflict" and that he does not get involved in such personal matters. After the conduct continues for several more months, Yael files an EEOC charge alleging that she was subjected to sex-based harassment. Under the circumstances, the investigator determines that Yael was subjected to a hostile work environment based on sex and that the employer is liable.

EXAMPLE 19 HOSTILE WORK ENVIRONMENT BASED ON PREGNANCY

Ramona, an account representative, had been working at a computer software company for five years when she became pregnant. Until then, she had been considered a "top performer," and had received multiple promotions and favorable evaluations. During Ramona's pregnancy, her supervisor, Henry, frequently made pregnancy-related comments, such as, "You look like a balloon; why don't you waddle on over here?" and, "Pregnant workers hurt the company's bottom line." Henry also began treating Ramona differently from other account representatives by, for example, asking for advance notification and documentation of medical appointments – a request that was not made of other employees who took leave for medical appointments nor of Ramona before her pregnancy.

After Ramona returned from maternity leave, Henry continued to treat her differently from other account representatives. For example, shortly after Ramona returned from maternity leave, Henry gave Ramona's coworkers an afternoon off so that they could attend a local fair as a "reward" for having covered Ramona's workload while she was on leave, but required Ramona to stay in the office and answer the phones. On another occasion, Ramona requested a schedule change so that she could leave earlier to pick up her son from daycare, but Henry denied the request without explanation, even though other employees' requests for schedule changes were granted freely, regardless of the reason for the request. Henry also continued to make pregnancy-related comments to Ramona on a regular basis. For example, after Ramona returned from maternity leave, she and Henry were discussing a coworker's pregnancy, and Henry sarcastically commented to Ramona, "I suppose you'll be pregnant again soon, and we'll be picking up the slack for you just like the last time."

Ramona complained about Henry's conduct to the Human Resources Manager, but he told her he did not want to take sides and that matters like schedule changes were within managerial discretion. After the conduct had continued for several months, Ramona filed an EEOC charge alleging that she had been subjected to a hostile work environment because of her pregnancy and use of maternity leave. Noting that Ramona experienced ongoing abusive conduct after she became pregnant, the investigator determines that Ramona has been subjected to a hostile work environment based on pregnancy and that the employer is liable.⁸⁶

EXAMPLE 20 HOSTILE WORK ENVIRONMENT BASED ON ASSOCIATION WITH AN INDIVIDUAL WITH A DISABILITY

Martin, a first-line supervisor in a department store, had an excellent working relationship with his supervisor, Adam, for many years. However, shortly after Adam learned that Martin's wife has a severe form of multiple sclerosis, his relationship with Martin deteriorated. Although Martin had always been a good performer, Adam repeatedly expressed his concern that Martin's responsibilities caring for his wife would prevent him from being able to meet the demands of his job. Adam removed Martin from team projects, stating that Martin's coworkers did not think that Martin could be expected to complete his share of the work "considering all of his wife's medical problems." Adam set unrealistic time frames for projects assigned to Martin and yelled at him in front of coworkers about the need to meet approaching deadlines. Adam also began requiring Martin to follow company policies that other employees were not required to follow, such as requesting leave at least a week in advance except in the

case of an emergency. Though Martin complained several times to upper management about Adam's behavior, the employer did nothing. Martin files an EEOC charge, and the investigator determines that the employer is liable for harassment on the basis of Martin's association with an individual with a disability.

III. RETALIATION

Employers are prohibited from retaliating against workers for opposing unlawful discrimination, such as by complaining to their employers about gender stereotyping of working mothers, or for participating in the EEOC charge process, such as by filing a charge or testifying on behalf of another worker who has filed a charge. Because discrimination against caregivers may violate the EEO statutes, retaliation against workers who complain about such discrimination also may violate the EEO statutes.⁸⁷

The retaliation provisions under the EEO statutes protect individuals against any form of retaliation that would be reasonably likely to deter someone from engaging in protected activity.⁸⁸ Caregivers may be particularly vulnerable to unlawful retaliation because of the challenges they face in balancing work and family responsibilities. An action that would be likely to deter a working mother from filing a future EEOC complaint might be less likely to deter someone who does not have substantial caregiving responsibilities. As the Supreme Court noted in a 2006 decision, "A schedule change in an employee's work schedule may make little difference to many workers, but may matter enormously to a young mother with school age children."⁸⁹ Thus, the EEO statutes would prohibit such a retaliatory schedule change or any other act that would be reasonably likely to deter a working mother or other caregiver from engaging in protected activity.

Footnotes

¹ For more information on the FMLA, see Compliance Assistance – Family and Medical Leave Act, <http://www.dol.gov/whd/fmla/> (U.S. Department of Labor web page); see also EEOC Fact Sheet, *The Family and Medical Leave Act, the Americans with Disabilities Act, and Title VII of the Civil Rights Act of 1964* (1995), <https://www.eeoc.gov/policy/docs/fmlaada.html> (discussing questions that arise under Title VII and the ADA when the FMLA also applies).

While federal law does not prohibit discrimination based on parental status, some state and local laws do prohibit discrimination based on parental or similar status. *E.g.*, ALASKA STAT. § 18.80.200 (prohibiting employment discrimination based on "parenthood"); D.C. Human Rights Act, D.C. CODE § 2-1402.11 (prohibiting employment discrimination based on "family responsibilities").

² In 1970, 43% of women were in the labor force while 59% of women were in the labor force in 2005. BUREAU OF LABOR STATISTICS, DEPT OF LABOR, *WOMEN IN THE LABOR FORCE: A DATABOOK 1* (2006) [hereinafter DATABOOK], <http://www.bls.gov/cps/wlf-databook-2006.pdf>.

³ AFL-CIO, *PROFESSIONAL WOMEN: VITAL STATISTICS* (2006), <http://www.pay-equity.org/PDFs/ProfWomen.pdf> (in 2005, women accounted for 46.4% of the labor force).

⁴ DATABOOK, *supra* note 2, Table 7 (59% of mothers with children under 3 were in the civilian labor force in 2005, compared with 34% in 1975).

⁵ BUREAU OF LABOR STATISTICS, DEPT OF LABOR, *WORKING IN THE 21ST CENTURY*, <http://www.bls.gov/opub/working/home.htm> (combined work hours per week for married couples with children under 18 increased from 55 hours in 1969 to 66 hours in 2000).

⁶ Testimony of Heather Boushey, Senior Economist, Center for Economic and Policy Research, to the EEOC, Apr. 17, 2007, <https://www.eeoc.gov/abouteeoc/meetings/4-17-07/boushey.html> ("For many families, having a working wife can make the difference between being middle class and not. . . . The shift in women's work participation is not simply about women wanting to work, but it is also about their families needing them to work.").

⁷ See generally Laura T. Kessler, *The Attachment Gap: Employment Discrimination Law, Women's Cultural Caregiving, and the Limits of Economic and Liberal Legal Theory*, 34 U. MICH. J.L. REFORM 371, 378-80 (2001) (discussing women's continued role as primary caregivers in our society and citing studies).

BUREAU OF LABOR STATISTICS, DEPT OF LABOR, *AMERICAN TIME-USE SURVEY* (2006), Table 8, <http://www.bls.gov/news.release/pdf/atus.pdf> (in 2005, in households with children under 6, working women spent an average of 2.17 hours per day providing care for household members compared with 1.31 hours for working men; in households with children 6 to 17, working women spent an average of .99 hours per day providing care for household members compared with .50 for working men).

⁸ See generally Peggie R. Smith, *Elder Care, Gender, and Work: The Work-Family Issue of the 21st Century*, 25 BERKELEY J. EMP. & LAB. L. 351, 355-60 (2004).

⁹ *Id.* at 360 (noting that women provide about 70% of unpaid elder care); see also *Nevada Dep't of Human Res. v. Hibbs*, 538 U.S. 721, 738 (2003) (noting that working women provide two-thirds of the nonprofessional care for older, chronically ill, and disabled individuals); Cathy D. Martin, *More Than the Work: Race and Gender Differences in Caregiving Burden*, 21 JOURNAL OF FAMILY ISSUES 986, 989-90 (2000) (discussing greater role women play in providing eldercare).

¹⁰ Smith, *supra* note 8, at 365-70.

¹¹ See BOSTON COLL. CTR. FOR WORK & FAMILY, *EXECUTIVE BRIEFING SERIES, EXPLORING THE COMPLEXITIES OF EXCEPTIONAL CAREGIVING* (2006) (contact the Center to order copies of the Executive Briefing Series, 617-552-2865 or cwf@bc.edu).

¹² See generally DEPT OF HEALTH & HUMAN SERVS., *INFORMAL CAREGIVING: COMPASSION IN ACTION* (1998) (hereinafter *INFORMAL CAREGIVING*), <http://aspe.hhs.gov/daltcp/reports/carebro2.pdf>.

¹³ U.S. CENSUS BUREAU, *DISABILITY AND AMERICAN FAMILIES: 2000*, at 3, 16 (2005), <http://www.census.gov/prod/2005pubs/censr-23.pdf>.

¹⁴ *INFORMAL CAREGIVING*, *supra* note 12, at 11.

¹⁵ See, e.g., Lynette Clemetson, *Work vs. Family, Complicated by Race*, N.Y. TIMES, Feb. 9, 2006, at G1 (discussing unique work-family conflicts faced by African American women).

¹⁶ For example, by 1900, 26% of married African American women were wage earners, compared with 3.2% of their White counterparts. JENNIFER TUCKER & LESLIE R. WOLFE, CTR. FOR WOMEN POLICY STUDIES, *DEFINING WORK AND FAMILY ISSUES: LISTENING TO THE VOICES OF WOMEN OF COLOR* 4 (1994) (citing other sources). More recently, in 1970, more than 70% of married African American middle-class women and nearly 45% of married African American working-class women were in the labor force compared with 48% and 32%, respectively, of their White counterparts. LONNAE O'NEAL PARKER, *I'M EVERY WOMAN: REMIXED STORIES OF MARRIAGE, MOTHERHOOD AND WORK* 29 (2005).

¹⁷ DATABOOK, *supra* note 2, Table 5 (in 2005, 68% of African American women with children under the age of 3 were in the workforce compared with 58% of White women, 53% of Asian American women, and 45% of Hispanic women).

¹⁸ POPULATION REFERENCE BUREAU, *Diversity, Poverty Characterize Female Headed Households*, <http://www.prb.org/Articles/2003/DiversityPovertyCharacterizeFemaleHeadedHouseholds.aspx> (about 5% of White or Asian American households are female-headed households with children compared with 22% of African American households and 14% of Hispanic households).

Native American women may have greater childcare responsibilities and are less likely to be employed than their White or African American counterparts. Native American women may have special family and community obligations based on tribal culture and often have more children than do White or African American women. Job opportunities may be further limited since Native American women often live in remote areas where the few available jobs tend to be in traditionally male-dominated industries. THE NATIVE NORTH AMERICAN ALMANAC 1088 (2d ed. 2001).

¹⁹ U.S. CENSUS BUREAU, *GRANDPARENTS LIVING WITH GRANDCHILDREN: 2000*, Table 1 (2003), <http://www.census.gov/prod/2003pubs/c2kbr-31.pdf> (showing a higher proportion of African American and Native American grandmothers responsible for raising grandchildren than White, Asian, or Hispanic grandmothers).

²⁰ See NAT'L ASS'N OF STATE UNITS ON AGING, *IN THE MIDDLE: A REPORT ON MULTICULTURAL BOOMERS COPING WITH FAMILY AND AGING ISSUES* (2001), <http://www.nasua.org/familycaregiver/rbv1/rbv1b11.pdf> (in survey of Baby Boomers in the "sandwich generation," one in five White respondents reported providing eldercare or financial assistance to their parents, compared with two in five Asian Americans or one in three Hispanics or African Americans); see also Karen Bullock et al., *Employment and Caregiving: Exploration of African American Caregivers*, SOCIAL WORK 150 (Apr. 2003) (discussing impact of eldercare responsibilities on employment status of African Americans).

²¹ Donna St. George, *Fathers Are No Longer Glued to Their Recliners*, WASH. POST, Mar. 20, 2007, at A11 (men's childcare work increased from 2.5 hours to 7 hours per week between 1965 and 2003). The total workload of married mothers and fathers combining paid work, childcare, and housework is about equal at 65 hours per week for mothers and 64 hours per week for fathers. *Id.*; see also SUZANNE BIANCHI ET AL., *CHANGING RHYTHMS OF AMERICAN FAMILY LIFE* (2006).

²² See, e.g., KAREN L. BREWSTER & BRYAN GIBLIN, *EXPLAINING TRENDS IN COUPLES' USE OF FATHERS AS CHILDCARE PROVIDERS*, 1985.2002, at 2.3 (2005), <http://www.fsu.edu/~popctr/papers/floridastate/05-151paper.pdf> (percentage of employed married women who relied on their husbands as the primary childcare provider increased from 16.6% in 1985 to 23.2% in 2002).

²³ See generally Joan C. Williams & Nancy Segal, *Beyond the Maternal Wall: Relief for Family Caregivers Who Are Discriminated Against on the Job*, 26 HARV. WOMEN'S L.J. 77 (2003) (discussing "maternal wall" discrimination, which limits the employment opportunities of workers with caregiving responsibilities). See also MARY STILL, UNIV. OF CAL., HASTINGS COLL. OF LAW, *LITIGATING THE MATERNAL WALL: U.S. LAWSUITS CHARGING DISCRIMINATION AGAINST WORKERS WITH FAMILY RESPONSIBILITIES* (2005), http://www.uchastings.edu/site_files/WLL/FRDreport.pdf (documenting rise in lawsuits alleging discrimination against caregivers).

²⁴ See generally JOAN WILLIAMS, UNIV. OF CAL., HASTINGS COLL. OF LAW, *ONE SICK CHILD AWAY FROM BEING FIRED: WHEN "OPTING OUT" IS NOT AN OPTION* (2006), <http://www.worklifelaw.org/pubs/onesickchild.pdf>.

²⁵ The median weekly earnings of full-time wage and salary workers in 2005 were \$596 for White women compared with \$499 for African American women and \$429 for Hispanic women. DATABOOK, *supra* note 2, Table 16. While the weekly median earnings for Asian American women, \$665, exceed the earnings of White women, *id.*, the earnings of Asian American women vary widely depending on national origin. See *Socioeconomic Statistics and Demographics*, Asian Nation, <http://www.asian-nation.org/demographics.shtml> (discussing the wide disparity in socioeconomic attainment rates among Asian Americans).

²⁶ ONE SICK CHILD AWAY FROM BEING FIRED, *supra* note 24, at 8.

²⁷ E.g., ONE SICK CHILD AWAY FROM BEING FIRED, *supra* note 24, at 23 (discussing case presented to arbitrator where employee with nine years of service was discharged for absenteeism when she left work after receiving a phone call that her four-year-old daughter had fallen and was being taken to the emergency room).

²⁸ EQUAL EMPLOYMENT OPPORTUNITY COMM'N, *GLASS CEILING: THE STATUS OF WOMEN AS OFFICIALS AND MANAGERS IN THE PRIVATE SECTOR* (2004), <https://www.eeoc.gov/stats/reports/glassceiling/index.html>.

²⁹ Diane Stafford, *Wanted: Women in the Workplace*, MONTEREY COUNTY HERALD, Apr. 5, 2006, available at 2006 WLNR 5689048.

³⁰ GOOD FOR BUSINESS: MAKING FULL USE OF THE NATION'S HUMAN CAPITAL, Washington, D.C.: U.S. Gov't Printing Office, at 3. The Glass Ceiling Commission was established under the Civil Rights Act of 1991 to complete a study of the barriers to advancement faced by women and minorities. A copy of the Commission's 1995 fact-finding report is available at http://digitalcommons.ilr.cornell.edu/key_workplace/116.

³¹ *Nevada Dep't of Human Res. v. Hibbs*, 538 U.S. 721, 738 (2003) (holding that the family-leave provision of the Family and Medical Leave Act is a valid exercise of congressional power to combat sex discrimination by the states); see also *Phillips v. Martin Marietta Corp.*,

400 U.S. 542, 545 (1971) (Marshall, J., concurring) (Title VII does not permit "ancient canards about the proper role of women to be a basis for discrimination").

³² *Hibbs*, 538 U.S. at 731 (in an FMLA claim brought by a male worker who was denied leave to care for his ailing wife, the Court noted that states' administration of leave benefits has fostered the "pervasive sex-role stereotype that caring for family members is women's work").

³³ See SHELLEY CORRELL & STEPHEN BENARD, *GETTING A JOB: IS THERE A MOTHERHOOD PENALTY?* (2005) (women with children were recommended for hire and promotion at a much lower rate than women without children).

³⁴ See *Knussman v. Maryland*, 272 F.3d 625, 629-30 (4th Cir. 2001) (male employee was not eligible for "nurturing leave" as primary caregiver of newborn unless his wife were "in a coma or dead").

³⁵ See § II.D, *infra* (discussing disparate treatment of women of color who are caregivers).

³⁶ This document addresses only disparate treatment, or intentional discrimination, against caregivers. It does not address disparate impact discrimination.

³⁷ See *Thomas v. Eastman Kodak Co.*, 183 F.3d 38, 61 (1st Cir. 1999) ("concept of 'stereotyping' includes not only simple beliefs such as 'women are not aggressive' but also a host of more subtle cognitive phenomena which can skew perceptions and judgments").

³⁸ *Price Waterhouse v. Hopkins*, 490 U.S. 228, 251 (1989) (plurality opinion).

³⁹ *Lust v. Sealy, Inc.*, 383 F.3d 580, 583 (7th Cir. 2004).

⁴⁰ For example, results of internal employee surveys as reported by Eli Lilly revealed that employees with the most flexibility and control over their hours reported more job satisfaction, greater sense of control, and less intention to leave than those on other schedules. CORPORATE VOICES FOR WORKING FAMILIES, *BUSINESS IMPACTS OF FLEXIBILITY: AN IMPERATIVE FOR EXPANSION* (2005) 13, http://www.cvworkingfamilies.org/flex_report/flex_report.shtml.

⁴¹ In a 2005 study, almost half of the employers that offer flexible work schedules or other programs to help employees balance work and family responsibilities stated that the main reason they did so was to recruit and retain employees, and one-quarter said they did so mainly to enhance productivity and commitment. FAMILIES AND WORK INST., NATIONAL STUDY OF EMPLOYERS 26 (2005), <http://familiesandwork.org/site/research/reports/2005nse.pdf>; see also Work Life, Fortune Special Section, http://www.timeinc.net/fortune/services/sections/fortune/corp/2004_09worklife.html (2004) (noting that "smart companies are retaining talent by offering employees programs to help them manage their work and personal life priorities").

⁴² For example, based on the proportion of workers who said they would have left in the absence of flexible workplace policies, the accounting firm Deloitte and Touche calculated that it saved \$41.5 million in turnover-related costs in 2003 alone. CORPORATE VOICES, *supra* note 40, at 10.

⁴³ See *Back v. Hastings on Hudson Union Free Sch. Dist.*, 365 F.3d 107, 121 (2d Cir. 2004) (female school psychologist with a young child could show that she was denied tenure because of her sex by relying on evidence of gender-based comments about working mothers and other evidence of sex stereotyping and was not required to show that similarly situated male workers were treated more favorably); *Plaetzer v. Borton Auto., Inc.*, No. Civ. 02-3089 JRT/JSM, 2004 WL 2066770, at *6 n.3 (D. Minn. Aug. 13, 2004) (evidence of more favorable treatment of working fathers is not needed to show sex discrimination against working mothers where an "employer's objection to an employee's parental duties is actually a veiled assertion that mothers, because they are women, are insufficiently devoted to work, or that work and motherhood are incompatible"); cf. *Lust*, 383 F.3d at 583 (reasonable jury could have concluded that the plaintiff's supervisor did not recommend her for a promotion because he assumed that, as a working mother, the plaintiff would not accept a promotion that would require her to move because of its disruptive effect on her children). But see *Phillipsen v. University of Mich. Bd. of Regents*, No. 06-CV-11977-DT, 2007 WL 907822 (E.D. Mich. Mar. 22, 2007) (holding that a plaintiff cannot establish a prima facie case of sex discrimination against women with young children in the absence of comparative evidence that men with young children are treated more favorably). While the Commission agrees that the plaintiff raised no inference of sex discrimination, it believes that cases should be resolved on the totality of the evidence and concurs with *Back* and *Plaetzer* that comments evincing sex-based stereotypical views of women with children may support an inference of discrimination even absent comparative evidence about the treatment of men with children.

⁴⁴ E.g., *Santiago-Ramos v. Centennial P.R. Wireless Corp.*, 217 F.3d 46, 55 (1st Cir. 2000) (comments by decisionmakers reflecting concern that the plaintiff might not be able to balance work and family responsibilities after she had a second child could lead a jury to conclude that the plaintiff was fired because of sex).

⁴⁵ *Sigmon v. Parker Chapin Flattau & Klimpl*, 901 F. Supp. 667, 678 (S.D.N.Y. 1995) (the plaintiff's only "deeply critical" performance evaluation was received shortly after she announced her pregnancy and therefore could be discounted).

⁴⁶ *Phillips v. Martin Marietta Corp.*, 400 U.S. 542, 544 (1971) (evidence showed that the employer had a policy of not hiring women with preschool age children, but did not have a policy of not hiring men with preschool age children).

⁴⁷ *Sigmon*, 901 F. Supp. at 678 (reasonable factfinder could conclude that the decreasing number of women in the corporate department was caused by sex discrimination where tension between female associates and the employer regarding the maternity leave policy contributed to the high separation rate of pregnant women and mothers).

⁴⁸ For more information on the kinds of evidence that may be relevant in a disparate treatment case, see EEOC Compliance Manual: *Race Discrimination*, Volume II, § 15-V, A.2, "Conducting a Thorough Investigation" (2006), <https://www.eeoc.gov/policy/docs/race-color.html#A2>.

⁴⁹ *Martin Marietta Corp.*, 400 U.S. at 545 (Title VII prohibits employer from hiring men with preschool age children while refusing to hire women with preschool age children). Some courts and commentators have used the term "sex plus" to describe cases in which the employer discriminates against a subclass of women or men, i.e., sex plus another characteristic, such as caregiving or marriage. See, e.g., *Phillipsen v. University of Mich. Bd. of Regents*, No. 06-CV-11977-DT, 2007 WL 907822, at *4 (E.D. Mich. Mar. 22, 2007) ("sex plus" discrimination is discrimination based on sex in conjunction with another characteristic); *Gee-Thomas v. Cingular Wireless*, 324 F. Supp. 2d

875 (M.D. Tenn. 2004) ("Title VII also prohibits so-called 'gender plus' or 'sex plus' discrimination, by which an employer discriminates, not against the class of men or women as a whole, but against a subclass of men or women so designated by their sex plus another characteristic."); Regina E. Gray, Comment, *The Rise and Fall of the "Sex Plus" Discrimination Theory: An Analysis of Fisher v. Vassar College*, 42 How. L. J. 71 (1998). In *Back*, the Second Circuit explained that the term "sex plus" is merely a concept used to illustrate that a Title VII plaintiff can sometimes survive summary judgment even when not all members of the protected class are subjected to discrimination. The Commission agrees with the *Back* court that, in practice, the term "sex plus" is "often more than a little muddy" and that the "[t]he relevant issue is not whether a claim is characterized as 'sex plus' or 'gender plus,' but rather, whether the plaintiff provides evidence of purposefully sex-discriminatory acts." 365 F.3d at 118-19 & n.8.

⁵⁰ *Lust v. Sealy, Inc.*, 383 F.3d 580, 583 (7th Cir. 2004) ("Realism requires acknowledgment that the average mother is more sensitive than the average father to the possibly disruptive effect on children of moving to another city, but the antidiscrimination laws entitle individuals to be evaluated as individuals rather than as members of groups having certain average characteristics."); see also *Manhart v. City of Los Angeles, Dep't of Water & Power*, 435 U.S. 702, 708 (1978) ("[Title VII's] focus on the individual is unambiguous. It precludes treatment of individuals as simply components of a racial, religious, sexual, or national class. . . . Even a true generalization about the class is an insufficient reason for disqualifying an individual to whom the generalization does not apply.").

⁵¹ *Back*, 365 F.3d at 121 (in a sex discrimination claim under 42 U.S.C. § 1983, the court stated that "where stereotypes are considered, the notions that mothers are insufficiently devoted to work, and that work and motherhood are incompatible, are properly considered to be, themselves, gender-based").

⁵² Marion Crain, "Where Have All the Cowboys Gone?" *Marriage and Breadwinning in Postindustrial Society*, 60 OHIO ST. L.J. 1877, 1893 (1999) ("[T]he cultural assignment to women of the primary responsibility for nurturing children and making a home undermines their performance in the market Women who are not caregivers may be adversely affected as well, because employers will assume that their attachment to the waged labor market is secondary.").

⁵³ Felice N. Schwartz, BREAKING WITH TRADITION: WOMEN AND WORK, THE NEW FACTS OF LIFE 9-26 (1992) (commenting that "even today, women sometimes are advised to remove their wedding rings when they interview for employment, presumably to avoid the inference that they will have children and not be serious about their careers"), cited in Williams & Segal, *supra* note 23, at 97; Edward J. McCaffery, *Slouching Towards Equality: Gender Discrimination, Market Efficiency, and Social Change*, 103 YALE L.J. 595, 631 n.124 (1993) (stating that "getting married itself is an act that sends out the wrong signal on this score [of commitment to the labor market] - that is, it does for women - and thus the evidence that married women hide their wedding rings prior to job interviews is not surprising").

⁵⁴ 42 U.S.C. § 2000e-3(m).

⁵⁵ *Id.* § 2000e-5(g)(2).

⁵⁶ *Back*, 365 F.3d at 120 ("it takes no special training to discern stereotyping in the view that a woman cannot 'be a good mother' and have a job that requires long hours, or in the statement that a mother who received tenure 'would not show the same level of commitment [she] had shown because [she] had little ones at home'").

⁵⁷ See Alice H. Eagly & Valerie J. Steffen, *Gender Stereotypes, Occupational Roles, and Beliefs About Part-Time Employees*, 10 PSYCH. WOMEN. Q. 252, 260-61 (1986) (finding that "[f]or women, part-time employment is generally associated with substantial domestic obligations, and female part-time employees are consequently perceived as similar to homemakers"). In contrast, part-time employment in men is associated with difficulty in finding full-time paid employment.

Courts are divided as to whether the practice of paying part-time workers at a lower hourly rate than full-time workers implicates the Equal Pay Act. Compare *Lovell v. BBNT Solutions, LLC*, 295 F. Supp. 2d 611, 620-21 (E.D. Va. 2003) (part-time female worker could compare herself with full-time male worker for purposes of establishing a prima facie case under the EPA), with *EEOC v. Altmeyer's Home Stores, Inc.*, 672 F. Supp. 201, 214 (W.D. Pa. 1987) (EEOC could not establish sex-based pay discrimination by comparing part-time worker with full-time worker). See also Section 10: *Compensation Discrimination*, § 10-IV F.2.h, EEOC Compliance Manual, Volume II (BNA) (2000).

⁵⁸ Employers may think that they are behaving considerately when they act on stereotypes that they believe correspond to characteristics that women should have, such as the belief that working mothers with young children should avoid extensive travel. See KATHLEEN FUEGEN ET AL., *Mothers and Fathers in the Workplace: How Gender and Parental Status Influence Judgments of Job-Related Competence*, 60 J. SOC. ISSUES 737, 751 (2004); Williams & Segal, *supra* note 23, at 95.

⁵⁹ *Lust*, 383 F.3d 580 (upholding jury's finding that employee was denied promotion based on sex where supervisor did not consider plaintiff for a promotion that would have required relocation to Chicago because she had children and he assumed that she would not want to move, even though she had never told him that and, in fact, had told him repeatedly that she was interested in a promotion despite the fact that there was no indication that a position would be available soon at her own office in Madison).

⁶⁰ Cf. *International Union, United Auto., Aerospace & Agric. Implement Workers of Am. v. Johnson Controls*, 499 U.S. 187, 199-200 (1991) (in rejecting employer policy that excluded fertile women from positions that would expose them to fetal hazards, the Court stated that the "beneficence of an employer's purpose does not undermine the conclusion that an explicit gender-based policy is sex discrimination").

⁶¹ See *Lettieri v. Equant Inc.*, 478 F.3d 640 (4th Cir. 2007) (evidence was sufficient for finder of fact to conclude that the plaintiff was denied a promotion because of discriminatory belief that women with children should not live away from home during the work week).

⁶² See *Thomas v. Eastman Kodak Co.*, 183 F.3d 38, 42, 59-61 (1st Cir. 1999) ("concept of 'stereotyping' includes not only simple beliefs such as 'women are not aggressive' but also a host of more subtle cognitive phenomena which can skew perceptions and judgments").

⁶³ See Amy J.C. Cuddy et al., *When Professionals Become Mothers, Warmth Doesn't Cut the Ice*, 60 J. SOC. ISSUES 701, 711 (2004) ("Not only are [working mothers] viewed as less competent and less worthy of training than their childless female counterparts, they are also viewed as less competent than they were before they had children. Merely adding a child caused people to view the woman as lower on traits such as capable and skillful, and decreased people's interest in training, hiring, and promoting her.").

⁶⁴ See *Back*, 365 F.3d at 115 (employer told employee that it was "not possible for [her] to be a good mother and have this job"); *Trezza v. Hartford, Inc.*, No. 98 CIV. 2205 (MBM), 1998 WL 912101, at *2 (S.D.N.Y. Dec. 30, 1998) (employer remarked to employee that, in attempting to balance career and motherhood, "I don't see how you can do either job well"); see also Cecilia L. Ridgeway & Shelley J. Correll, *Motherhood as a Status Characteristic*, 60 J. SOC. ISSUES 683, 690 (2004) (noting that while mothers are expected always to be

"on call for their children," a worker is expected to be "unencumbered by competing demands and be always there for his or her employer").

⁶⁵ See, e.g., Nicole Buonocore Porter, *Re-defining Superwoman: An Essay on Overcoming the "Maternal Wall" in the Legal Workplace*, 13 DUKE J. GENDER L. & POL'Y 55, 61-62 (Spring 2006).

⁶⁶ See *infra* § II.C.

⁶⁷ See *supra* § II.A.1.

⁶⁸ For information on protections under the Family and Medical Leave Act, see Compliance Assistance – Family and Medical Leave Act, <http://www.dol.gov/whd/fmla/>.

⁶⁹ *International Union, United Auto., Aerospace & Agric. Implement Workers of Am. v. Johnson Controls*, 499 U.S. 187, 204 (1991).

⁷⁰ Title VII defines the terms "because of sex" or "on the basis of sex" as including "because of or on the basis of pregnancy, childbirth, or related medical conditions" and provides that "women affected by pregnancy, childbirth, or related medical conditions shall be treated the same for all employment-related purposes . . . as other persons not so affected but similar in their ability or inability to work." 42 U.S.C. § 2000e(k).

⁷¹ Some employers' improper pregnancy-related "inquiries" have even included pregnancy testing. See, e.g., *Justice Department Settles Pregnancy Discrimination Charges Against D.C. Fire Department*, U.S. FED. NEWS, Sept. 8, 2005, 2005 WLNR 14256220 (reporting on settlement between DOJ and District of Columbia regarding complaint that employment offers as emergency medical technicians were contingent on negative pregnancy test result and that technicians who became pregnant during first year of employment were threatened with termination).

⁷² See EEOC Enforcement Guidance: *Disability-Related Inquiries and Medical Examinations of Employees Under the Americans with Disabilities Act*, Question 2 (2000), <https://www.eeoc.gov/policy/docs/guidance-inquiries.html> ("A 'medical examination' is a procedure or test that seeks information about an individual's physical or mental impairments or health.") (emphasis added). For information on the ADA's specific restrictions on the use of medical examinations, see 29 C.F.R. §§ 1630.13, .14 & Appendix to Part 1630.

⁷³ 29 C.F.R. Part 1604 Appendix, Question 5 (1978).

⁷⁴ Cf. *Troy v. Bay State Computer Group, Inc.*, 141 F.3d 378 (1st Cir. 1998).

⁷⁵ This document supersedes EEOC's *Policy Guidance on Parental Leave* (Aug. 27, 1990).

⁷⁶ *Hibbs*, 538 U.S. at 736.

⁷⁷ See *Williams & Segal*, *supra* note 23, at 101-02 (discussing stereotypes of men who take active role in childcare).

⁷⁸ For information on protections under the Family and Medical Leave Act, see Compliance Assistance – Family and Medical Leave Act, <http://www.dol.gov/whd/fmla/>.

⁷⁹ See *California Fed. Sav. & Loan Ass'n v. Guerra*, 472 U.S. 272, 290 (1987) (upholding state pregnancy disability-leave statute requiring employers to provide leave for the period of time that a woman is physically disabled by pregnancy, childbirth, and related medical conditions).

⁸⁰ This period includes the postpartum period that a woman remains incapacitated as a result of having given birth. See generally Pat McGovern et al., *Postpartum Health of Employed Mothers 5 Weeks After Childbirth*, ANNALS OF FAMILY MEDICINE, Mar. 2006, at 159, available at <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1467019>.

⁸¹ See EEOC Compliance Manual: Race Discrimination, Volume II, § 15-IV, C, "Intersectional Discrimination" (2006), <https://www.eeoc.gov/policy/docs/race-color.html#IVC>.

⁸² 42 U.S.C. § 12112(b)(4). Section 501 of the Rehabilitation Act provides the same protection to federal workers. 29 U.S.C. § 791(g) (Incorporating ADA standards).

⁸³ *Abdel-Khalke v. Ernst & Young, LLP*, No. 97 CIV 4514 JGK, 1999 WL 190790 (S.D.N.Y. Apr. 7, 1999) (issues of fact regarding whether employer refused to hire applicant because of concern that she would take time off to care for her child with a disability).

⁸⁴ 29 U.S.C. § 1630.8 (ADA makes it unlawful for employer to "deny equal jobs or benefits to, or otherwise discriminate against," a worker based on his or her association with an individual with a disability) (emphasis added).

⁸⁵ 29 C.F.R. § 1604.11 (Sexual Harassment Guidelines); *EEOC Policy Guidance on Current Issues of Sexual Harassment* (Mar. 19, 1990) (sex-based harassment – harassment not involving sexual activity or language – may give rise to Title VII liability if it is "sufficiently patterned or pervasive"), <https://www.eeoc.gov/policy/docs/currentissues.html>.

⁸⁶ This example is based on *Walsh v. National Computer Systems, Inc.*, 332 F.3d 1150 (8th Cir. 2003) (upholding jury verdict that the plaintiff was subjected to a hostile work environment in violation of Title VII when she was harassed because she had been pregnant, taken pregnancy-related leave, and might become pregnant again).

⁸⁷ E.g., *Gallina v. Mintz, Levin, Cohn, Ferris, Glosky & Popeo, P.C.*, Nos. 03-1883, 03-1947, 2005 WL 240390 (4th Cir. Feb. 2, 2005) (unpublished) (plaintiff presented sufficient evidence for reasonable jury to conclude that she was denied a pay raise and terminated for complaining about harassment and other adverse conduct that began after the acting manager learned that the plaintiff had a small child).

⁸⁸ See *Burlington N. & Santa Fe Ry. Co. v. White*, 126 S. Ct. 2405, 2415 (2006) ("plaintiff must show that a reasonable employee would have found the challenged action materially adverse, 'which in this context means it well might have "dissuaded a reasonable worker from making or supporting a charge of discrimination"'") (citations omitted).

⁸⁹*Id.*

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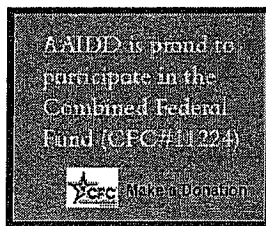
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Autonomy, Decision-Making Supports, and Guardianship

Joint Position Statement of AAIDD and The Arc

Statement

All individuals with intellectual and/or developmental disabilities (I/DD)[1] have the right to recognition as persons before the law and to enjoy legal capacity on an equal basis with individuals who do not have disabilities in all aspects of life (United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), 2006). The personal autonomy, liberty, freedom, and dignity of each individual with I/DD must be respected and supported. Legally, each individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each individual with I/DD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.

Issue

- Current trends presume the decision-making capacity of individuals with I/DD and the preservation of legal capacity as a priority for all people needing assistance with decision-making.
- Like their peers without disabilities, individuals with I/DD must be presumed competent; they must also be assisted to develop as decision-makers through education, supports, and life experience. Communication challenges should not be misinterpreted as lack of competency to make decisions.
- Individuals with I/DD should have access to supports and experiences to learn decision-making skills from an early age and throughout their lifetimes in educational and adult life service systems.
- Families should have access to information about all options for assisting their family member to make decisions over the life course.
- All people, with and without disabilities, have a variety of formal and informal processes available to enact their decisions and preferences, including healthcare proxies and advance directives.
- Less restrictive means of decision-making supports (e.g., health-care proxies, advance directives, supported decision-making, powers of attorney, notarized statements, representation agreements, etc.) should be tried and found to be ineffective in ensuring the individual's decision-making capacity before use of guardianship[2] as an option is considered.
- Where judges and lawyers lack knowledge about people with I/DD and their human rights, poor advocacy and tragic legal outcomes often result. Financial incentives frequently benefit professionals and guardianship corporations, often to the detriment of individuals with I/DD and their families.
- Serving in the dual roles of guardian and paid service provider or paid advocate creates a conflict of interest or the appearance of a conflict of interest. Such conflicts must be mitigated or avoided.
- Some statutory privacy measures have made it more difficult for those assisting other individuals to have access to their records, make decisions, or both. Thus, to obtain or modify needed medical care, services, and supports, an individual with I/DD may be adjudicated to be incompetent and subjected to guardianship. This result conflicts with the legal presumption of competence and with principles of autonomy, decision-making supports, presumption of competence, and the use of less restrictive alternatives.

The appointment of a guardian is a serious matter for three reasons: (1) It limits an individual's autonomy, that is, the individual's agency over how to live and from whom to receive supports to carry out that choice; (2) It transfers the individual's rights of autonomy to another individual or entity, a guardian; and (3) Many individuals with I/DD experience guardianship as stigmatizing and inconsistent with their exercise of adult roles and responsibilities.

Position

The primary goals in assisting individuals with I/DD should be to assure and provide supports for their personal autonomy and ensure equality of opportunity, full participation, independent living, and economic self-sufficiency (Americans with Disabilities Act, 1990, section 12101 (a)(7); Individuals with Disabilities Education Act, 2004, section 1400 (c)(1)). Each individual adult and emancipated minor is legally presumed competent to make decisions for himself or herself and should receive the preparation, opportunities, and decision-making

supports to develop as a decision-maker over the course of his or her lifetime. All people with I/DD can participate in their own affairs with supports, assistance, and guidance from others, such as family and friends. People with I/DD should be aware of and have access to decision-making supports for their preferred alternatives.

- If legal limitations on autonomy are necessary, then National Guardianship Association or equivalent standards that are consistent with the values expressed in this position statement should be followed. If any restrictions on autonomy are legally imposed, each individual has the right to the least restrictive alternative, due process protections, periodic review, ongoing training and supports to enhance autonomy and reduce reliance on approaches that restrict individual rights, and the right to ultimately seek to restore rights and terminate the restriction when possible.
- Information and training about less restrictive alternatives to guardianship should be available to people with I/DD, their family members, attorneys, judges, and other professionals.
- If the use of a guardianship becomes necessary, it should be limited to the fewest restrictions necessary for the shortest amount of time and tailored to the individual's specific capacities and needs.
- Strict monitoring must be in place to promote and protect the autonomy, liberty, freedom, dignity, and preferences of each individual even when placed under guardianship.
- Regardless of their guardianship status, all individuals with I/DD should be afforded opportunities to participate to the maximum extent possible in making and executing decisions about themselves. Guardians should engage individuals in the decision-making process, ensuring that their preferences and desires are known, considered, and achieved to the fullest extent possible.
- Regardless of their guardianship status, all individuals with I/DD retain their fundamental civil and human rights (such as the right to vote and the right to make decisions related to sexual activity, marriage and divorce, birth control, and sterilization) unless the specific right is explicitly limited by court order.

Systems Issues

- States should provide systematic access to decision-making supports for all individuals with I/DD.
- An individual (other than a family member) should not serve in dual roles as guardian and as paid advocate or paid service provider for an individual.
- An organization should avoid serving in dual roles as guardian and as paid advocate or paid service provider for an individual.
- Organizations that serve in dual roles of guardian and paid advocate or paid service provider must have written policies and organizational separations in place to mitigate conflicts of interest. These organizations should support efforts to develop independent guardianship organizations.
- Financial incentives that benefit professionals or guardianship corporations should never drive guardianship policy or result in expensive and unnecessary costs to individuals or their families.
- Appointment of a guardian of the person, the person's finances, or both, should be made only to the extent necessary for the legal protection and welfare of the individual and not for the convenience or preferences of the family, the service system, or others.
- Individuals with I/DD must have access to all the accommodations and supports, including communication supports, they need to demonstrate their competency at initial evaluations for guardianship and at all periodic reviews of any guardianship.
- State laws should be reformed to prioritize less restrictive alternatives to full and plenary guardianship, including without limitation informal supports, supported decision-making, limited (and revocable) powers of attorney, health care proxies, trusts, and limited guardianships that are specifically tailored to the individual's capacities and needs. These alternatives should always be considered first. Use of these alternatives can help an individual who may have limited capacity to consent to satisfy statutory privacy or other requirements and to have records released to a person or entity designated as the individual's agent or provider of support and services. If used at all, any restrictions on the individual's rights and decision-making powers should be confined to those areas in which the individual demonstrates a need for assistance that exceeds what can be provided through a less restrictive alternative.
- Laws should be reformed to require that less restrictive options are tried and found to be ineffective to ensure the individual's autonomy before full (plenary) guardianship is even considered. Alternatives and related procedures to change overly restrictive forms of any existing guardianship, including restoration of rights and termination of any guardianship, must be available under state law.
- Since guardianship represents a transfer of rights and the responsibility for exercising them, adequate safeguards must be in place to protect those rights. These safeguards include procedural due process (including without limitation the right to counsel representing the interests of the individual, impartial hearing, appeal, and burden and quantity of proof) must protect the individual's autonomy. The state must also ensure that the individual is informed and retains as much decision-making power as possible. The state should pay the costs of providing these due process protections and not impose the costs on families or on individuals with I/DD.
- Members of the judiciary, attorneys, and other professionals need training and education on alternatives to guardianship for individuals with I/DD, and they must zealously advocate for preserving the substantive and procedural rights of all individuals with I/DD.
- If a guardian is to be appointed, the preferences and assent of the individual with I/DD with respect to the identity and function of the proposed guardian should be considered.

- The appointment of a guardian should be appropriately time-limited in order to provide regular periodic review of the individual's current capabilities and functioning and whether a less restrictive alternative is now indicated. The reviews should include an independent professional assessment by a highly qualified examiner of the individual's functioning with necessary accommodations and communication supports. All costs of the review should be paid by the state and not imposed on individuals with I/DD or their families.
- Guardianship should include a person-centered plan of teaching and/or supports for decision making so the individual with I/DD will have opportunities to learn and practice the skills needed to be autonomous and to direct his or her own life. Understanding the nature and purpose of guardianship and understanding that most people with I/DD can manage their own affairs with assistance and guidance should be part of transition planning in schools and of any curriculum or procedures that prepare the individual's person-centered plan for adulthood. Schools should not give legal advice to students and families, and should provide students and families with information about less restrictive alternatives to guardianship.
- The ultimate goal of any such curriculum or procedures should be to ensure the individual's autonomy to the maximum extent possible, individualize decision-making supports for the individual, and ensure that the individual has maximum access to equal opportunity, independent living, full participation, and economic self-sufficiency, each with supports that take into account the individual's capacities and needs.

Guardian Responsibilities

- Guardians should be knowledgeable about decision-making and other types of supports, services, and systems that can significantly affect the individual's autonomy, supports, and quality of life. Moreover, guardians must be committed to the individual's well-being and avoid any appearance or actual lack of commitment to the individual. They must know and understand the individual's needs and wishes and act in accordance with them whenever possible and whenever any action will not negatively affect the individual's health, safety, financial security, and other welfare. Family members are often preferable choices when a guardianship is ordered and the family members meet these standards of knowledge, they do not have conflicts of interest (other than also serving as a paid advocate or paid service provider), and the individual with I/DD does not object to the family member's appointment as guardian.
- Guardians shall defer to the individual's preferences when decisions do not jeopardize the individual's health, safety, financial security, and other welfare.

Oversight

- States should adopt a set of minimum standards for all guardians and require training and technical assistance for all guardians.
- Professional guardians (those who both serve two or more people who are not related to each other and also receive fees for these services) should, at a minimum, be registered, and preferably licensed or certified by the state, either directly or through delegation to an appropriate independent professional organization. They should also have the appropriate education and skills. They should be independent from and not be receiving payment for providing other services to the individual.
- Guardians shall be legally accountable for all of their decisions and other actions with respect to the individual. Their decisions and other actions must be subject to the reporting and review procedures of the appropriate state court or other agency.

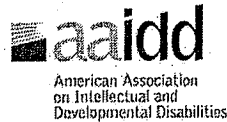
[1] "People with intellectual disability (ID)" refers to those with "significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18", as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), published by the American Psychiatric Association (APA, 2013). "People with developmental disabilities (DD)" refers to those with "a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are lifelong or extended duration and are individually planned and coordinated," as defined by the Developmental Disabilities Assistance and Bill of Rights Act 2000. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.

[2] Terminology for guardianship and guardians differs by state and can include tutor, conservator, curator, or other comparable terms.



The Arc

For people with intellectual
and developmental disabilities



POSITION STATEMENT **Self Determination**

People with intellectual and/or developmental disabilities¹ have the same right to self-determination as all people. They must have opportunities and experiences that enable them to exert control in their lives and to advocate on their own behalf.

Issue

Many of our constituents have not had the opportunity or the support to control choices and decisions about important aspects of their lives. Instead, they are often overprotected and involuntarily segregated. Many of these people have not had opportunities to learn the skills and have the experiences that would enable them to take more personal control and make choices. The lack of such learning opportunities and experiences has impeded the right of people with these disabilities to become participating, valued, and respected members of their communities. Furthermore, state monitoring and licensure policies and practices may be contrary to the principles of self-determination.

Position

Our constituents, as Self Advocates, have the same right to self-determination as all people and must have the freedom, authority, and support to exercise control over their lives. To this end, they must:

In their personal lives have:

- opportunities to advocate for themselves with the assurance that their desires, interests, and preferences will be respected and honored.
- opportunities to acquire and use skills and knowledge which better enable them to exercise choice.
- the right to take risks.
- the right to choose their own allies.

The Arc
1825 K Street, NW
Suite 1200
Washington, D.C. 20006
Phone: 202.534.3700
Toll free: 800.433.5255
Fax: 202.534.3731
www.thearc.org

- the lead in decision-making about all aspects of their lives.
- the option to self-direct their own supports and services and allocate available resources.
- the choice and support necessary to hire, train, manage, and fire their own staff.
- opportunities to take leadership roles in setting the policy direction for the self-determination movement.
- the right to representation and meaningful involvement in policy-making at the federal, state, and local levels.

In their community lives have:

- the right to receive the necessary support and assistance to vote.
- opportunities to be supported to become active, valued members and leaders of community boards, advisory councils, and other organizations.

"People with intellectual and/or developmental disabilities" refers to those defined by AAIDD classification and DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

Adopted:
Congress of Delegates, The Arc of the United States
2011

Achieve with us.

For more information on this and other topics, visit www.thearc.org

ENDLESS POSSIBILITIES
A COMPARISON OF DECISION MAKING OPTIONS IN DELAWARE

Who Completes the Form	Supportive Decision Making (Proposed)	Surrogate Decision Making	Advanced Health-Care Directive	Power of Attorney	Guardianship
	The adult, two witnesses, and the Supporter.	Determination is made by the attending physician if patient lacks capacity, or stated by the patient if able.	The adult, with or without medical or legal consultation.	The adult, with or without legal consultation.	A petition and multiple forms must be filed by the person seeking guardianship with the Court of Chancery.
Type of Document	Document-executed and witnessed indicating what type of assistance is needed and what the supporter has permission to do.	Documented-by-the physician in the patient's health record as to who is designated by the patient, or who is available to serve.	Legal document stating a person's preferences to guide future health care treatment if the adult loses decision-making capacity, and may appoint an agent.	Legal document appointing an agent to manage financial affairs on behalf of the adult prior to or when the adult loses capacity.	Court Order specifying the powers of the guardian and what, if any, rights are retained by the individual.
Intended Population	Individuals who need help in gathering and assessing information, including those with physical disabilities, cognitive or intellectual disabilities, brain injuries, and the elderly.	Patients in the health care setting with or without decision making capacity.	All adults that have even a modest level of capacity, who are aware and able to understand the nature and effect of the document. (Testamentary capacity)	All adults that have even a modest level of capacity, who are aware and able to understand the nature and effect of the document. (Testamentary capacity)	All individuals assessed by a physician to have no decision making capacity, or those at risk of harm or exploitation.

Signatures required	Document must be signed by the adult, two witnesses, and the appointed Supporter.	Confirmed in writing by the physician if patient lacks capacity, or by the physician and the witness if decision maker designated by patient.	Person and two witnesses meeting specific requirements.	Document must be signed, witnessed and notarized.	Court Order signed by a Judicial Officer.
Appointment of Authorized Representative	Appoints an individual to gather information and assist in assessing information. Supporter does not have individual authority.	A person may designate a surrogate decision maker by informing the health care provider in the presence of a witness, or if unable to do so, the health care provider may recognize an individual pursuant to the law. (16 Del.C. §2507)	Title 16, Chapter 25 provides a form which must be executed to set out the wishes of the person and appoint an agent who may act when the individual becomes incapacitated.	Title 12, Chapter 49A provides a statutory form and directions for appointing an agent.	The Court of Chancery appoints a guardian upon the petition. Title 12, Chapter 39.
Role of Representative	To provide support to the adult, including help in assessing information, options, responsibilities and consequences of the adult's life decisions, including those about health care, financial decisions, and support services.	To make decisions about health care in place of the individual.	To make decisions about health care in place of the individual in conformance with their wishes.	To make decisions in place of the individual about financial matters.	To assume all decision making in place of the individual, who retains not ability to make decisions for themselves. Authority extends to both person and property depending on the order of the Court.
Termination of Power	May be revoked by individual.	A competent person may disqualify a surrogate in writing or by communicating with the care provider.	May be revoked in writing or another means of effective communication the intent to revoke.	May be revoked by the individual.	The guardianship may be terminated upon petition to the Court of Chancery if the individual recovers capacity, or terminates upon death.