MEMORANDUM

To: SCPD Policy & Law Committee

From: Brian J. Hartman

Re: Recent Legislative & Regulatory Initiatives

Date: April 11, 2016

Consistent with the requests of the SCPD and GACEC, I am providing an analysis of thirteen (13) legislative and regulatory initiatives. Given time constraints, the analysis should be considered preliminary and non-exhaustive.

1. DOE Final New Teacher Hiring Data Reporting Reg. [19 DE Reg. 91’9 (4/1/16)]

   The SCPD and GACEC commented on the proposed version of this regulation in February. A copy of the SCPD’s February 22, 2016 letter is attached for facilitated reference. The Department of Education has now adopted a final regulation with one revision prompted by the commentary.

   First, the Councils suggested substituting “Data” for “Date” in the title to the regulation. The DOE agreed and effected the substitution.

   Second, the Councils suggested that the Department consider substituting “educator” for “teacher” if the DOE reporting form includes staff apart from teachers. The DOE anomalously notes that data on specialists such as nurses is collected in the report but it declined to expand the reference to “educator”.

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

2. DPH Revised Final DMOST Regulation [19 DE Reg. 922 (4/1/16)]

   The Division of Public Health published a proposed Delaware Medical Orders for Scope of Treatment ("DMOST") regulation in November. The SCPD and GACEC commented on the initiative resulting in several amendments incorporated into the final regulation adopted in January, 2016. See attached January 29, 2016 SCPD letter for a summary of revisions.
The Division is now issuing a revised final regulation to address technical matters and correct typographical errors. At 922. Agencies can publish such revised regulations as “final” if they are non-substantive in nature. See Title 29 Del.C. §10113(b). Using the link in the PDF version of the regulation, I reviewed the latest version of the regulation which is published in very small type and single spaced. It does not “earmark” changes so I could not easily identify the revisions. Since they would amount to non-substantive edits, the Councils may wish to consider taking no action. The Division is not soliciting comments.

3. DOE Prop. Skilled & Technical Sciences Teacher Reg. [19 DE Reg. 882 (4/1/16)]

The Department of Education proposes to amend its qualification standards for a “skilled and technical sciences teacher”.

The current regulation (§4.0) generally imposes the following qualification standards:

1) 9 career-related credits in area of certification and 6 technical education pedagogy credits; AND

2) either a Bachelor’s Degree in any content area or Associate’s Degree plus 21 specified credits or 2 years of college or technical training plus 15 specified credits; AND

3) 6 years of work experience or teaching in the career area, 2 of which must be in the last 5 years; AND

4) if occupation requires a State license or certification, a valid and current Delaware license.

The current regulation allows an applicant to substitute an Associate’s degree for 1 year of work experience and a Bachelor’s degree for 2 years of work experience. The DOE proposes to double these standards to “2” and “4” years respectively:

“Work Experience” means full time employment or work training experience in the specific Skilled and Technical Sciences career area of certification. An educator may substitute an Associate’s degree in the specific Skilled and Technical Sciences career area for a maximum of one two years of work experience or a Bachelor’s degree in the specific Skilled and Technical Sciences career area of certification for a maximum of two four years of work experience.
The effect of the change is to dilute the qualifications of the Skilled and Technical Sciences Teacher. For example, the current standards would authorize certification if an applicant with a Bachelor’s degree has 4 years of work experience. Under the new standards, an applicant would be certified with a Bachelor’s degree and 2 years of work experience. Since the DOE offers no rationale for the proposed change, it is difficult to assess justification for the dilution in standards. Perhaps the Department views this dilution of qualifications as justified given a shortage of candidates who meet the current standard. Given the lack of a disability nexus, and lack of a rationale for the amendment, the Councils may wish to share the above observations while taking no position on the proposed regulation.

4. DMMA Prop. LTC Facility Personal Needs Allowance Reg. [19 DE Reg. 893 (4/1/16)]

The Division of Medicaid & Medical Assistance proposes to raise the personal needs allowance for Medicaid-funded individuals residing in long-term care facilities.

Under CMS regulations, Medicaid-funded individuals residing in long-term care facilities are generally required to contribute to costs of institutional services after deducting certain allowable amounts. At 894, quoting 42 CFR §435.725. One deduction is a “personal needs allowance (PNA)” which, for “aged, blind, or disabled” persons must be at least $30/month for individuals and $60/month for couples. Id. The purpose of the PNA is to provide an “allowance that is reasonable in amount for clothing and other personal needs of the individual while in the institution”.

The current PNA established by DMMA is $44/month for individuals and $88/month for couples. These amounts have not changed in 14 years, i.e., since 2002. At 894. The Division proposes to increase the PNA from $44/month to $50/month for individuals and from $88/month to $100/month for couples. The change would be effective July 1, 2016. The change is “subsidized” by federal funds. For example, in FFY17, the projected fiscal impact of the change is $71,596 in federal funds and $60,500 in State funds. At 895.

I have the following observations.

First, DMMA could consider a larger increase in the PNA. Consistent with the attachment, $44 in 2002 equates to $57.99 in 2016 based on inflation. Adopting a $50 rate reflects an increase of less than half the inflation rate. Moreover, since the State infrequently changes the rate, adopting an overly restrained benchmark in 2016 which will remain in effect for many years will accentuate the disparity. DMMA could consider adopting a $58 rate for individuals and a $116 rate for couples which would fully account for the inflation rate. This would ostensibly raise the State fiscal impact from $60,500 to $141,167 while increasing the federal contribution from $71,596 to $167,057.
Second, on p. 896, DMMA may wish to consider substituting “ICF/IID for ICF/MR. See CMS attachment, Title 29 Del.C. §608, and DMMA references to ICF/IID at 19 DE Reg. 888, 889 and 892.

Third, on p. 897, the following reference should be reconsidered in consultation with DDDS:

If the recipient regularly attends a rehab/educational program off the grounds of his nursing or her long-term care facility, including employment for the purpose of rehabilitation in a sheltered workshop off the grounds of the facility, $50.00 per month (rather than $44) will be protected; ...

The reference is somewhat archaic given Title 19 Del.C. §§740-747 (Employment First Act) and could be interpreted as excluding PNA eligibility to participants in supported employment as well as day habilitation programs. It may violate public policy to limit PNA to participants (including group home and foster home residents) in sheltered workshops to the exclusion of participants in supported employment.

Fourth, on p. 897, there are two references to an SGA limit of $700. That was the SGA limit in 1999-2000. See attachment. There is also an incorrect reference to “Department of Social Services (DSS)” rather than Department of Health & Social Services and references to “DSS” that ostensibly should be “DMMA”.

Fifth, on p. 897, the reference to “unimpaired people” should be reconsidered. See Title 29 Del.C. §608.

The Councils may wish to share the above observations with DMMA, DDDS, the Employment First Commission, and AARP. The Councils may also wish to share at least the first observation with the co-chairs of the JFC.

5. DMMA Prop. Drug Rebate Agreement Regulation [19 DE Reg. 884 (4/1/16)]

The Division of Medicaid & Medical Assistance proposes to amend its Medicaid State Plan in the context of its drug rebate agreement.

As background, drug manufacturers are required to offer rebates on drugs used in the Medicaid program. States may enter into separate or supplemental drug rebate agreements as long as they achieve drug rebates equal to or greater than the drug rebates contained in a national HHS rebate agreement. At 885. Delaware currently participates in a multi-state purchasing pool (“TOP$”) which generates rebates. However, DMMA proposes to discontinue participation in “TOP$” and enroll in the “SSDC” pool based on the following rationale:
The administration of the TOP$ Medicaid multi-state purchasing pool has (since) changed. This change has caused costs to increase, and made DMMA’s ability to administer the drug rebate program more difficult. The Sovereign State Drug Consortium (SSDC) Medicaid multi-state purchasing pool provides states with more options and control when negotiating supplemental rebate rates, and allows for easier administration of the drug rebate program.

At 885. Enrollment in the new pool would be effective July 1, 2016. There would be no direct impact on Medicaid beneficiaries:

The agency’s proposal involves no change in the definition of those eligible to receive pharmaceutical services, and the Medicaid prescribed drugs benefit available to eligible recipients remains the same. In addition, the agency’s proposal involves no change to providers’ current practices.

At 886.

I did not identify any concerns with the proposed Medicaid State Plan amendment. Since the switch to a new pool is expected to provide increased flexibility and easier administration of the drug rebate program, the Councils may wish to consider endorsement.

6. DMMA Prop. Medicaid LTC “Bed Hold” Payment Regulation [19 DE Reg. 888 (4/1/16)]

The Division of Medicaid & Medical Assistance proposes to amend its Medicaid “bed hold” standards applicable to long-term care facilities.

As background, a CMS regulation (42 CFR §447.40) allows states, at state option, to make “bed hold” payments to a long-term care facility during a resident’s temporary absence due to hospitalization or other specified reasons. At 889. DMMA currently implements this option but plans to modify it for residents of an ICF/IID. In a nutshell, the normal paid 7-day bed-hold period per hospitalization would be extended to 14 days for Delaware’s only ICF/IIDs - Stockley Center and Mary Campbell Center. The expected fiscal impact for FFY17 is $25,000 in State funds and $29,585 in federal funds. At 890-891.

I have the following observations.

First, on p. 889, the reference to 42 CFR §440.40 is incorrect. The reference should be to 42 CFR §447.40.
Second, consistent with 42 CFR §447.40, DMMA reaffirms the current policy of allowing up to 18 days per calendar year of “bed-hold” payments if included in the resident’s plan of care. At 891. It would be informative to include the following clarifying sentence after Par. “2” on p. 891: “This may include absences included in a plan of care due to transfers to a ‘specialized treatment facility’ consistent with Title 16 Del.C. §1121(18).” This would be instructive to providers and residents seeking to reconcile Medicaid payment standards and the overlapping State “bed -hold” statute. For similar reasons, the same sentence could be added to §20650.2.1 on p. 892.

Third, waiver of the 18 day paid leave of absence limit can be obtained if the LTC facility applies and its medical director confirms medical necessity. This may be unduly limiting. It would be preferable to allow either the LTC facility or the resident [supported by his personal attending physician [16 Del.C. §1121(21)] to apply for a waiver since a resident’s view may be different than the facility’s view. CMS recognizes the divergence of interest in the context of transfers and discharges. See 42 C.F.R. §483.12(a)(3)(i ); attached CMS Surveyor Guidance F201-203; and attached CMS proposed regulations, 80 Fed Reg. 42247-42249, 42254-42255. For example, the facility may prefer that the resident or resident’s family “private pay” for the period in excess of 18 days since that results in higher payment.

The Councils may wish to consider endorsement of the extended paid “bed-hold” period for ICF/IID’s while also sharing the above observations with DMMA, DDDS, and AARP.


The Division of Medicaid & Medical Assistance proposes to amend the Medicaid State Plan to address coverage and reimbursement of treatment services for beneficiaries up to age 21 with a diagnosis of autism spectrum disorder (“ASD”).

As background, CMS issued the attached July 7, 2014 guidance outlining approaches to provide Medicaid services to eligible individuals with ASD. CMS noted that services often “fit” under the following categories: 1) other licensed practitioner services; 2) preventive services; 3) therapy services; 4) waivers; and 5) EPSDT benefit. See also related articles. DMMA is now implementing the guidance by adopting conforming Medicaid State Plan amendments.

I have the following observations.

First, there is some “tension” between the proposed requirement that a Medicaid beneficiary be “under 21 years of age” to qualify for “autism spectrum disorder treatment services” (p. 900) and special education eligibility extending to the end of the school year in which a student turns 21. See Title 14 Del.C. §3101(1). The age standard is ostensibly based on the EPSDT age limit but EPSDT should not be the sole eligibility basis for autism-related services. Moreover, “other licensed practitioner services”, “preventive services”, and “therapy services” are not limited to individuals under age 21.
Second, ASD services are barred if an individual is not "medically stable". Therefore, individuals with the most severe medical needs are anomalously ineligible for services. For example, query whether a beneficiary would be unable to obtain occupational or physical therapy services to remediate an "unstable" medical condition (e.g. helmet or assistive technology to address head banging or SIBS). Conceptually, the autism treatment services may be necessary to achieve medical stability.

Third, ASD services are barred if an individual qualifies for ICF/IID placement. This would ostensibly exclude anyone enrolled in the DDDS waiver (in which eligibility begins at age 12) which categorically requires that participants meet an ICF/IID level of care. See attached excerpts from DDDS waiver.

Fourth, the projected fiscal impact of the regulation is high, i.e., $1,223,105 in State funds in FFY17. Since the identified services (other licensed practitioner services; preventative services; therapy) are already covered by the State Plan, it's unclear why the projected fiscal impact is so high. Moreover, since private insurers must cover treatment of autism spectrum disorders (S.B. No. 22 from 146th General Assembly), private insurance should cover most services if an individual has both Medicaid and private health insurance.

Fifth, an individual cannot obtain a functional behavioral assessment, a behavioral support plan, or any ASD treatment services until a licensed medical professional under Delaware State regulation completes an evaluation. See Attachment 3.1-A, Page 6 Addendum 1a. This categorical requirement appears unduly strict if an individual with an ASD diagnosis for years, perhaps based on an out-of-state evaluation, desires a behavioral support plan or ASD services.

Sixth, there is some "tension" between the following requirements:

These evaluations may not be performed by the same professional who delivers or supervises the beneficiary's direct ASD treatment.

Attachment 3.1-A, Page 6 Addendum 1b (describing neurodevelopmental review by psychologists and psychiatrists).

The provider who develops the behavioral plan of care should be the same provider who performed the behavioral assessment, except in extenuating circumstances, ...

Attachment 3.1-A, Page 6 Addendum 1g.

As a practical matter, it may be impractical and counterproductive to exclude an evaluator from also providing services. This is not the standard model within the Delaware Medicaid program. For example, an ST, OT, or PT often performs an assessment of need, develops a treatment plan, and provides therapy pursuant to the plan.
Seventh, the sources of information for the functional behavioral assessment includes everyone but the individual with the ASD diagnosis. See Attachment 3.1-A, Page 6, Addendum 1c. It would be preferable to include the individual in the list which otherwise includes schools, family, pediatricians, etc.

Eighth, DMMA may wish to amend the following provision in Attachment 3.1-A, Page 6, Addendum 1d by adding the underlined language: "(6) The use of Behavior Modifying Medications without a formal assessment and diagnosis of a corresponding mental health disorder by physician or advance practice registered nurse." See 24 Del.C. §1902.

Ninth, in Attachment 3.1-A, Page 6 Addendum 1e, Par (12), DMMA may wish to substitute "individual" for "child".

Tenth, the following requirement is highly objectionable:

(e) Presence/Availability of Caregiver. In order to ensure that the services are covered under the preventive services benefit category and do not include non-coverable services such as child care, respite, or related services, as well as to ensure the clinical success of the services, a caregiver must be present and/or available in the setting where services are being provided at all times (even when not directly participating in the services) in order to care for individuals under the age of eighteen.

Attachment 3.1-A, Page 6 Addendum 1f.

This is a discriminatory requirement which "stereotypes" all individuals under 18 with an ASD diagnosis as requiring 24/7 care under constant adult supervision. It is not required that parents of minors with other conditions be physically present on-site when a minor receives Medicaid services. There are 17 year old individuals with Aspergers who could drive themselves to an appointment and have absolutely no need for parental accompaniment. Moreover, the statement that "respite" is categorically a "non-coverable" service is incorrect. It is a covered service under the DSHP+ program and may be available under the EPSDT benefit.

Eleventh, the following utilization limit is highly objectionable:

(f) Limitations on ASD Treatment Services: Total ASD treatment services from all sources may only be the amount medically necessary for each individual, up to 25 hour (sic "hours") per week, which may be exceeded with prior authorization based on medical necessity.

Attachment 3.1-A, Page 6 Addendum 1f.

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A. This limitation is at odds with the EPSDT expectation that covered individuals will receive all Medicaid services needed to ameliorate conditions identified through screening and assessment. See Attachment 3.1-A, Page 6 Addendum 1. See also attached CMS EPSDT guidance:

The goal of this benefit is to ensure that children under the age of 21 who are enrolled in Medicaid receive age-appropriate screening, preventive services, and treatment services that are medically necessary to correct or ameliorate any identified conditions - the right care to the right child at the right time in the right setting. This broad scope supports a comprehensive, high-quality health benefit.

At 3.

NHeLP characterizes attempts to place hard caps on ASD services as illegal under EPSDT:

Another common problem is that some states place hard limits on the hours of service Medicaid will provide in a week or a month. These limits, which are illegal under EPSDT, prevent children with the highest need from getting all the medically necessary care to which they are entitled. (See CMS, EPDST Coverage Guide at 23).

NHeLP, "Autism Spectrum Disorders", Health Advocate (October, 2015) at 3 (attached).

The CMS EPSDT Guide is corroborative:

Because medical necessity decisions are individualized, flat limits or hard limits based on a monetary cap or budgetary constraints are not consistent with EPSDT requirements. ...For example, while a state may place in its State Plan a limit of a certain number of physical therapy visits per year for individuals age 21 and older, such a “hard” limit could not be applied to children.

At 23-24 (attached). Although CMS suggests some leeway with “soft” limits incorporated into medical necessity standards, DMMA is not amending its medical necessity regulation. Rather, it is manifestly imposing a cap based on budgetary considerations.

B. There is no comparable cap on ST, OT, or PT, preventive services, and other licensed practitioner services in the Medicaid State Plan generally so imposing a cap simply because a beneficiary has an ASD diagnosis is ostensibly impermissible discrimination under the ADA and Section 1557 of the ACA. See attachment.

The Councils may wish to consider sharing the above observations with DMMA and autism advocacy organizations. The Councils may also wish to consider sharing the observations with CMS.
8. S.B. No. 214 (Employment Discrimination)

This legislation was introduced on March 24, 2016. As of April 11, it awaited action by the Senate Labor & Industrial Relations Committee.

As background, Delaware law currently imposes a 120-day statute of limitation for the filing of an employment discrimination complaint. This includes complaints based on the “Persons with Disabilities Employment Protections Act”. See Title 19 Del.C. §§712 and 727. The 120-day standard does not conform to federal law. Consistent with the attached excerpt from the EEOC Website, the statute of limitation is 300 days for states whose departments of labor are authorized to process complaints:

IX. What Agency Handles a Charge that Is also Covered by State or Local Law?

Many states and localities have anti-discrimination laws and agencies responsible for enforcing those laws. EEOC refers to these agencies as “Fair Employment Practices Agencies (FEPAs)”. Through the use of “work sharing agreements”, EEOC and the FEPAs avoid duplication of effort while at the same time ensuring that a charging party’s rights are protected under both federal and state law.

VIII. What Are the Time Limits for Filing a Charge of Discrimination?

...There are strict time limits within which charges must be filed:

- A charge must be filed with EEOC within 180 days from the date of the alleged violation, in order to protect the charging party’s rights.

- This 180-day filing deadline is extended to 300 days if the charge is also covered by state or local anti-discrimination law.

[emphasis supplied]

S.B. No. 214 conforms the State statute of limitations to match the above federal standard, i.e., 300 days. This is highly preferable for multiple reasons. First, individuals looking at the current Delaware Code may be misled into believing they only have 120 days to file a charge under both federal and state law. Second, it facilitates the administration of the State Department of Labor to have a State charge time line equal to the federal standard. Under current law, Delawareans who file charges within 120 days can have their claims processed by the State while those filing between 121-300 days have their claims routed to the federal EEOC for processing. See attached excerpt from Delaware DOL Website. This is an awkward and confusing system for consumers.

For the above reasons, the Councils may wish to consider endorsement.
9. H.B. No. 211 (Youth Shackling)

This legislation was introduced on March 17, 2016. As of April 11, it had been approved by the House Judiciary Committee but awaited action by the House Appropriations Committee.

Background on the bill is provided by the attached January 23, January 30, and March 16, 2016 News Journal articles. In a nutshell, the bill would bar automatic use of restraints (e.g. handcuffs; chains; straitjackets) for juveniles appearing in Family Court delinquency proceedings. The Court could authorize use of restraints only on a case-by-case basis justified by findings that restraints are necessary and there are no less restrictive alternatives (lines 32 - 48). The preamble to the bill, as well as the 3 attached articles, underscore the reasons why shackling of juveniles should be limited. It undermines the presumption of innocence, is demeaning and traumatizing, and deters dialog. Since minorities are statistically more likely to be placed in juvenile detention facilities, the use of shackles is disproportionately applied to minorities. According to the January 23 article, 71.8% of juveniles admitted to detention facilities in Delaware are minorities - “making it seven time more likely that African-American youth will be placed in a state detention center than white youth.”

According to the January 23, 2016 article, “twenty-three states have banned the practice of juvenile shackling by legislation or court order” and “about half of those have done so since 2014.” Many prominent organizations are supporting a national initiative to ban or reduce the use of restraints in delinquency proceedings (lines11-20). For example, the American Academy of Child & Adolescent Psychiatry issued a policy statement characterizing the routine shackling of juveniles as “demeaning, humiliating, and stigmatizing” and contributing to trauma (lines 14-16).

The bill is accompanied by the attached $232,996.24 fiscal note. It envisions the hiring of four YRS counselors to “enable two YRS staff members to be present with each youth in a court room.”

Given the compelling justification for the legislation, the Councils may wish to consider endorsement. The Councils may wish to share commentary with the Public Defender and ACLU.

10. S.B. No. 221 (Employer Tax Credit: DVR & DVI Referrals)

This legislation was introduced on March 24, 2016. As of April 11, it awaited action by the Senate Finance Committee.

As background, only 34.5% of non-institutionalized Americans ages 21-64 with a disability are employed. The Delaware statistic is similar, i.e., only 36.1% of such adults with a disability are employed. See attachment. Delaware has several laws which promote the hiring of individuals with disabilities (lines 5-6 and 16 Del.C. §5503). In the past few years, multiple programs have been initiated to “jump-start” training and employment opportunities for this constituency. Such initiatives include the DHSS Pathways to Employment program and the PROMISE program. See attached summaries. These programs are helpful but may be limited to certain age groups and disabilities. For example, individuals with traumatic brain injury, the “signature” injury of the Iraq and Afghanistan conflicts, do not qualify for either program.
Federal tax incentives exist to promote hiring of individuals with disabilities. See attachment. Many states, including Maryland and New York, offer a State tax credit to supplement the federal incentives. See attached article.

S.B. No. 221 is similar to proposed legislation shared by the Councils with the JFC in February, 2013. S.B. No. 221 authorizes a State tax credit for employers who hire referrals from the Division of Vocational Rehabilitation or the Division for the Visually Impaired after January 1, 2017. The amount of the credit would be equal to 10%, but in no event greater than $1,500, of the gross wages paid to a qualifying person. The credit would be available for the year in which the employee is hired and the 2 taxable years thereafter (lines 28-38).

One advantage to linking the credit to DVR referrals is that DVR is not limited to only certain disabilities. DVR serves individuals with a wide range of physical and mental impairments, including traumatic brain injury. It focuses on individuals with “most significant” and “significant” disabilities. Consistent with the attached excerpt from 2015 Annual Report from DVR’s Rehabilitation Council, in FY15 it served 7,757 clients of whom 2,861 were new applicants. It achieved a successful employment outcome for 1,138 clients with an average hourly wage of approximately $10.50/hour. The availability of a State tax credit should bolster DVR’s prospects for securing successful employment outcomes since hiring DVR referrals will be more attractive to employers.

Since the employment rate for Delawareans with disabilities is very low (36.1%), and this legislation would encourage the hiring of individuals with disabilities, the Councils may wish to consider endorsement.

11. S.B. No. 186 (Disabled Veteran School Tax Refund Fund)

This legislation was introduced on January 28, 2016. As of April 11, it awaited action by the Senate Finance Committee.

The bill (lines 39-42) would establish a fund of $3,000,000 to cover the cost of maximum school tax refunds as follows:

- $200 for qualified veteran with a V.A. disability rating of 10% to 20%;
- $350 for qualified veteran with a V.A. disability rating of 30% to 50%;
- $500 for a qualified veteran with a V.A. disability rating of 60% or higher.

A qualified veteran would have to be legally domiciled in the State and the credit would only apply to the veteran’s principal residence (lines 32-38). Consistent with the attached fiscal note, the legislation is expected to benefit approximately 4,346 veteran homeowners in Delaware. Likewise, the fiscal note anticipates that the average refund under the bill would be $368.
I have the following observations.

First, the reference to “disabled veteran” does not reflect “people-first” language and is ostensibly disfavored under Title 29 Del.C. §608.

Second, at first glance, the references in lines 40-42 appeared “underinclusive” since they omitted disability ratings between 21-29% and 51%- 59%. However, consistent with the attached article, the V.A. system only uses 10% increments in its disability rating system so the references are accurate.

Third, if claims exceed the amount in the “Disabled Veteran School Tax Refund Fund”, the “shortfall” may be derived from “the general contingency appropriation in the Department of Education” (lines 8-9). Since the attached fiscal note only contemplates an annual cost of $1.6 million of the $3.0 million fund, there may not be a shortfall in the near future. However, this feature of the legislation may be of some concern to public educational interests.

Fourth, New Castle County already reduces the assessed value of homes owned by qualifying persons with disabilities. Consistent with the attached NCC summary, qualifying individuals are eligible for the following subsidy:

School Tax - They receive a reduction in their assessed value of up to $32,000. For loss of limbs or loss of limbs requiring home to be equipped with special fixtures, an additional $42,000 may be added to a maximum of $74,000. ... If the disability is Armed Forces Related, the taxpayer may receive an additional reduction of $5,000 off the assessed value of the residence for both County and School Taxes.

Thus, a veteran with a service-connected disability in New Castle County would ostensibly benefit from both a reduced “countable” assessment and the school tax refund authorized by this legislation.

Since the legislation would benefit veterans with disabilities, and prioritize a higher refund based on extent of service-connected disability, the Councils may wish to consider endorsement.

12. H.B. No. 268 (Substance Exposed Infants & Medically Fragile Children)

This legislation was introduced on March 3, 2016. As of April 11, it awaited action by the House Judiciary Committee.

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 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. 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).

I have the following observations.

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 it 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)
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.

The Councils may wish to consider 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.

The Councils may wish to share commentary with other disability advocacy agencies, the Attorney General, and the Public Defender.
13. H.B. No. 214 (Nurse Workplace Violence Protection)

This legislation was introduced on June 30, 2015. On March 23, 2016, it was released from the House Public Safety and Homeland Security Committee. As of April 11, it awaited action by the House. I previously provided a condensed analysis of the bill to the GACEC which resulted in submission of the attached March 24 memo to the General Assembly. The attached Committee report includes the following commentary: “The committee found that the language in this bill needs to be reworked in order to address punishments for individuals who are mentally handicapped.”

I have the following observations.

Under current law, if a person intentionally causes “physical injury” to a member of the general public, the crime is a misdemeanor A punishable by up to 1 year in prison. See attached 11 Del.C. §§611 and 4206. There is special statute [11 Del.C. § 612] which elevates the misdemeanor to a felony D if a person intentionally causes “physical injury” to a nurse “while [the nurse] is rendering emergency care”. The penalty for a class D felony is up to 8 years in prison. See attached 11 Del.C. §4205(b). The definition of “physical injury” is “impairment of physical condition or substantial pain”. See attached 11 Del.C. §222(23). Therefore, the current law elevates the maximum 1 year prison term to a maximum 8 year term for an assault on a nurse providing emergency care with no significant injury apart from “pain”. H.B. No. 214 would expand the application of the 8-year prison term to nurses in non-emergency contexts, i.e., while “performing a work-related duty” (lines 17-18). While well intentioned, my concern is that authorizing a prison term not double, triple, or quadruple but 8 times in length for an assault resulting only in some pain seems disproportionate to the offense. One compromise would be to elevate the offense against a nurse to a felony F or G which carry 2 and 3 year prison terms respectively.

Authorizing excessive prison term runs counter to recent, high-publicized legislative initiatives to deter sentences disproportionate to the offense. See attached March 27, 2016 and April 3, 2016 News Journal articles. The March article highlights the following information:

Nationally, lawmakers are revisiting the tough sentencing laws that made the United States the world’s number 1 jailer. In recent years, voices from the left and right have joined together in challenging the scale of incarceration. Delaware has engaged in similar efforts too, but lags behind the country in downscaling its prison population....The growth of incarceration in Delaware resulted from the choices of lawmakers to increase the use and severity of prison sentences. Delaware’s correctional population has grown by more than 207 percent since 1980; taxpayers spend more than $32,900 to incarcerate each prisoner.
Policymakers may wish to consider unintended consequences. The bill could easily result in prosecution of patients with compromised capacity at the time of the alleged crime. For example, individuals with urinary tract infections may display symptoms akin to mental illness. Individuals with an intense fear of needles may defensively strike out at a nurse attempting to perform an injection. An elderly patient may strike out defensively at a nurse attempting to impose wrist or mechanical restraints on the patient to prevent the patient from removing tubes or aggravating wounds. Medications or a high fever may compromise executive functioning and self-control. A patient who does not speak English may defensively try to block an injection or push a nurse away out of a lack of understanding. A patient may experience involuntary movements or seizures which a nurse could misinterpret as voluntary acts of aggression. A patient with an undiagnosed TBI may strike out as a function of brain injury. The “unintended consequence” of the bill may be to unnecessarily “criminalize” a large number of vulnerable patients.

Finally, I am dubious that there would be any practical deterrent effect if the legislation were enacted. It is unlikely that aggressive or disoriented patients will deliberate and gauge their behavior based on whether an assault is a misdemeanor versus a felony under the Delaware Code.

In conclusion, while well intentioned, the legislation ostensibly authorizes a penalty disproportionate to the offense and may unnecessarily “criminalize” a large number of vulnerable patients.

The SCPD may wish to share the above observations with policymakers, including the Attorney General, Public Defender, and ACLU.

Attachments

E:legis/416bills
F:pub/bjh/legis/2016p&l/416bills
February 22, 2016

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

RE: 19 DE Reg. 712 [DOE Proposed New Teacher Hiring Data Reporting 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 covering district reporting of information on hiring of teachers. The proposed regulation was published as 19 DE Reg. 712 in the February 1, 2016 issue of the Register of Regulations. It requires districts to report hiring and vacancy information based on a DOE form. The DOE contemplates compilation of data into an annual report issued by March 31. SCPD has only two (2) observations.

First, the title of the regulation refers to “775 New Teacher Hiring Date Reporting”. Since the title of the report has changed to “an Educator Hiring Practices and Needs Report” (§3.0) from “New Teacher Hiring Date Report”, the DOE could consider a revised title. Perhaps “Data” could be substituted for “Date” based on §1.0.

Second, if the DOE form includes positions apart from teachers, the title and §1.0 could be revised to refer to “educator” hiring data. This would conform to the reference in §3.0 to “Educator Hiring Practices and Needs Report”.

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

Sincerely,

[Signature]

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
January 29, 2016

Mr. Jamie Mack
Division of Public Health
Jesse Cooper Building
417 Federal Street
Dover, DE 19901

RE: 19 DE Reg. 637 [DPH Final DMOST Regulation (1/1/16)]

Dear Mr. Mack:

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Health and Social Services/Division of Public Health’s (DPH’s) final regulation to repeal and replace its Delaware Medical Orders for Scope of Treatment (“DMOST”) regulation. The final regulation was published as 19 DE Reg. 637 in the January 1, 2016 issue of the Register of Regulations. SCPD commented on the proposed version of this regulation in November. DPH has now adopted a final regulation incorporating several amendments prompted by the commentary.

First, the Council recommended an amendment to clarify that an AHCD valid in another state would qualify under the regulatory definition of AHCD. The Division agreed and adopted a conforming amendment.

Second, the Council recommended consideration of additional safeguards for persons with communication deficits. The Division added safeguards to §7.7.2.

Third, the Council recommended inclusion of a reference to “effective communication” based on the ADA. A conforming reference was added to §4.7.

Fourth, the Council identified a grammatical error in the DMOST form. The error was corrected.

Fifth, the Council identified an ambiguity in the signature line in the DMOST form. The Division edited the form.

Sixth, the Council recommended an edit to highlight a form provision addressing the representative’s authority to alter a DMOST. The Division altered the format for greater clarity.

SCPD certainly appreciates that the Division adopted edits consistent with each of the Council’s comments.
Sincerely,

[Signature]

Mary Mullin-Powell, Chairperson
State Council for Persons with Disabilities

cc: Ms. Karyl Rattay, DHSS-DPH
Ms. Deborah Gottschalk, DHSS
Mr. Brian Hartman, Esq.
Developmental Disabilities Council
Governor's Advisory Council for Exceptional Citizens
19reg637 dph DMOST TY 1-27-16
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 2002 (enter year)
I purchased an item for $44.00
then in 2016 (enter year)
that same item would cost: $57.99
Cumulative rate of inflation: 31.8%

CALCULATE


INFLATION (http://WWW.USINFLATIONCALCULATOR.COM/CATEGORY/INFLATION/)


US consumer prices declined in February alongside plunging gasoline but underlying inflation advanced more than expected, a government report released on Wednesday, March 16, shows. Costs climbed for a broad section of goods and services to include big ticket items like shelter and medical care.

Overall in the past 12 months, inflation eased compared to the annual rate of a month earlier yet the pace clocked higher than any other since late 2014.
Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)

Publication date:
1985

Effective date:
1986

CFR section numbers:
483.400 – 483.480

CFR section descriptions:

Based on changes made in Rosa’s Law in 2010, Intermediate Care Facilities for Individuals with Mental Retardation (ICF/MR) will now reflect nationwide changes and be referred to as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID).

Sections 483.400 – 483.480 are located in Part 483 of the Code of Federal Regulations, Subpart I- Conditions of Participation for Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID). These CoPs establish the health and safety requirements that ICF/IID providers must meet in order to participate in the Medicare and Medicaid programs. The health and safety requirements address topics such as the provider’s governing body, client protections, facility staffing, facility environment, and services provided.

Brief description of document(s):

The links below provide more detailed information about the CoPs for ICF/IID providers, surveyor guidelines, payment policy information, and the statutory authority governing ICF/IID providers.
Substantial Gainful Activity

To be eligible for disability benefits, a person must be unable to engage in substantial gainful activity (SGA). A person who is earning more than a certain monthly amount (net of impairment-related work expenses) is ordinarily considered to be engaging in SGA. The amount of monthly earnings considered as SGA depends on the nature of a person's disability. The Social Security Act specifies a higher SGA amount for statutorily blind individuals; Federal regulations specify a lower SGA amount for non-blind individuals. Both SGA amounts generally change with changes in the national average wage index.

Amounts for 2016
The monthly SGA amount for statutorily blind individuals for 2016 is $1820. For non-blind individuals, the monthly SGA amount for 2016 is $1130. SGA for the blind does not apply to Supplemental Security Income (SSI) benefits, while SGA for the non-blind disabled applies to Social Security and SSI benefits. See historical series of SGA amounts below.

Trial work period
After a person becomes eligible for disability benefits, the person may attempt to return to the work force. As an incentive, we provide a trial work period in which a beneficiary may have earnings and still collect benefits.

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* $500 amount applied in the first half of 1999.
Transmittals for Appendix PP

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hospitalization or therapeutic leave, and whose absence exceeds the bed-hold period as defined by the State plan, to return to the facility in the first available bed. (See §483.12(b).)

A resident cannot be transferred for non-payment if he or she has submitted to a third party payor all the paperwork necessary for the bill to be paid. Non-payment would occur if a third party payor, including Medicare or Medicaid, denies the claim and the resident refused to pay for his or her stay.

§483.10(o), Tag F177, addresses the right of residents to refuse certain transfers within an institution on the basis of payment status.

F201

§483.12(a)(2) Transfer and Discharge Requirements

The facility must permit each resident to remain in the facility, and not transfer or discharge the resident from the facility unless—

(i) The transfer or discharge is necessary for the resident’s welfare and the resident’s needs cannot be met in the facility;

(ii) The transfer or discharge is appropriate because the resident’s health has improved sufficiently so the resident no longer needs the services provided by the facility;

(iii) The safety of individuals in the facility is endangered;

(iv) The health of individuals in the facility would otherwise be endangered;

(v) The resident has failed, after reasonable and appropriate notice, to pay for (or to have paid under Medicare or Medicaid) a stay at the facility. For a resident who becomes eligible for Medicaid after admission to a nursing facility, the nursing facility may charge a resident only allowable charges under Medicaid; or

(vi) The facility ceases to operate.

SEE GUIDANCE UNDER TAG 202

F202

(Rev. 127, Issued: 11-26-14, Effective: 11-26-14, Implementation: 11-26-14)

§483.12(a)(3) Documentation

When the facility transfers or discharges a resident under any of the circumstances specified in paragraphs (a)(2)(i) through (v) of this section, the resident’s clinical record must be documented. The documentation must be made by—
(i) The resident’s physician when transfer or discharge is necessary under paragraph (a)(2)(i) or paragraph (a)(2)(ii) of this section; and

(ii) A physician when transfer or discharge is necessary under paragraph (a)(2)(iv) of this section.

Interpretive Guidelines: §483.12(a)(2) and (3)

If transfer is due to a significant change in the resident’s condition, but not an emergency requiring an immediate transfer, then prior to any action, the facility must conduct the appropriate assessment to determine if a new care plan would allow the facility to meet the resident’s needs. (See §483.20(b)(4)(iv), F274, for information concerning assessment upon significant change.)

Conversion from a private pay rate to payment at the Medicaid rate does not constitute non-payment.

Refusal of treatment would not constitute grounds for transfer, unless the facility is unable to meet the needs of the resident or protect the health and safety of others.

Documentation of the transfer/discharge may be completed by a physician extender unless prohibited by State law or facility policy.

If a nursing home discharges a resident or retaliates due to an existing resident’s failure to sign or comply with a binding arbitration agreement, the State and Region may initiate an enforcement action based on a violation of the rules governing resident discharge and transfer. A current resident is not obligated to sign a new admission agreement that contains binding arbitration.

Procedures: §483.12(a)(2) and (3)

During closed record review, determine the reasons for transfer/discharge.

If the entity to which the resident was discharged is another long term care facility, evaluate the extent to which the discharge summary and the resident’s physician justify why the facility could not meet the needs of this resident.

Probes: §483.12(a)(2) and (3)

Do records document accurate assessments and attempts through care planning to address resident’s needs through multi-disciplinary interventions, accommodation of individual needs and attention to the resident’s customary routines?

Did the resident’s physician document the record if:
The resident was transferred/discharged for the sake of the resident’s welfare and the resident’s needs could not be met in the facility (e.g., a resident develops an acute condition requiring hospitalization)? or

The resident’s health improved to the extent that the transferred/discharged resident no longer needed the services of the facility.

Did a physician document the record if residents were transferred because the health of individuals in the facility is endangered?

Do the records of residents transferred/discharged due to safety reasons reflect the process by which the facility concluded that in each instance transfer or discharge was necessary? Did the survey team observe residents with similar safety concerns in the facility? If so, determine differences between these residents and those who were transferred or discharged.

Look for changes in source of payment coinciding with transfer. If you find such transfer, determine if the transfers were triggered by one of the criteria specified in §483.12(a)(2).

- Ask the ombudsman if there were any complaints regarding transfer and/or discharge. If there were, what was the result of the ombudsman’s investigation?

F203
(Rev. 107, Issued: 04-04-14, Effective: 04-04-14, Implementation: 04-04-14)

§483.12(a)(4) Notice Before Transfer

Before a facility transfers or discharges a resident, the facility must—

(i) Notify the resident and, if known, a family member or legal representative of the resident of the transfer or discharge and the reasons for the move in writing and in a language and manner they understand.

(ii) Record the reasons in the resident's clinical record; and

(iii) Include in the notice the items described in paragraph (a)(6) of this section.

§483.12(a)(5) Timing of the notice.

(i) Except when specified in paragraph (a)(5)(ii) of this section, the notice of transfer or discharge required under paragraph (a)(4) of this section must be made by the facility at least 30 days before the resident is transferred or discharged.

(ii) Notice may be made as soon as practicable before transfer or discharge when—
or money without the resident's consent.

Neglect is the failure of the facility, its employees or service providers to provide goods and services to a resident that are necessary to avoid physical harm, pain, mental anguish or mental illness.

Nurse aide. A nurse aide is any individual providing nursing or nursing-related services to residents in a facility. This term may also include an individual who provides these services through an agency or under a contract with the facility, but is not a licensed health professional, a registered dietitian, or someone who volunteers to provide such services without pay.

Nurse aides do not include those individuals who furnish services to residents only as paid feeding assistants as defined in § 483.301 of this chapter.

Person-centered care. For purposes of this subpart, person-centered care means to focus on the resident as the locus of control and support the resident in making their own choices and having control over their daily lives.

Resident representative. For purposes of this subpart, the term resident representative means an individual of the resident's choice who has access to information and participates in healthcare discussions or a personal representative with legal standing, such as a power of attorney, legal guardian, or health care surrogate appointed or designated in accordance with state law. If selected as the resident representative, the same-sex spouse of a resident must be afforded treatment equal to that afforded to an opposite-sex spouse if the marriage was valid in the jurisdiction in which it was celebrated.

Sexual abuse is non-consensual sexual contact of any type with a resident.

Transfer and discharge includes movement of a resident to a bed outside of the certified facility whether that bed is in the same physical plant or not. Transfer and discharge does not refer to movement of a resident to a bed within the same certified facility.

13. Section 483.10 is revised to read as follows:

§ 483.10 Resident rights.

The resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility, including those specified in this section.

(a) Exercise of rights. (1) The resident has the right to exercise his or her rights as a resident of the facility and as a citizen or resident of the United States.

(2) The resident has the right to be free of interference, coercion, discrimination, and reprisal from the facility in exercising his or her rights and to be supported by the facility in the exercise of his or her rights as required under this subpart.

(3) A resident has the right to designate a representative, in accordance with State law.

(i) The resident representative has the right to exercise the resident's rights to the extent those rights are delegated to the resident representative.

(ii) The resident retains the right to exercise those rights not delegated to a resident representative, including the right to revoke a delegation of rights, except as limited by State law.

(4) In the case of a resident adjudged incompetent under the laws of a State by a court of competent jurisdiction, the rights of the resident devolve to and are exercised by the resident representative appointed under State law to act on the resident's behalf.

(5) The resident may exercise his or her rights to the extent not prohibited by court order.

(i) The court-appointed resident representative exercises the resident's rights to the extent judged necessary by a court of competent jurisdiction, in accordance with State law.

(2) The resident's wishes and preferences must be considered in the exercise of rights by the representative.

(4) To the extent practicable, the resident must be provided with opportunities to participate in the care planning process.

(5) In the case of a resident who has not been adjudged incompetent by the state court, any legal surrogate designated with state law may exercise the resident's rights to the extent provided by state law. The same-sex spouse of a resident must be afforded treatment equal to that afforded to an opposite-sex spouse if the marriage was valid in the jurisdiction in which it was celebrated.

(b) Planning and implementing care. The resident has the right to be informed of, and participate in, his or her treatment, including:

(1) The right to be fully informed in language that he or she can understand of his or her total health status, including but not limited to, his or her medical condition.

(2) The right to be informed, in advance, of the care to be furnished and the disciplines that will furnish care.

(3) The right to be informed in advance of the risks and benefits of proposed care, of treatment and treatment alternatives or treatment options and to choose the alternative or option he or she prefers.

(4) The right to request, refuse, and/or discontinue treatment, to participate in or refuse to participate in experimental research, and to formulate an advance directive as specified in § 483.11(e)(6).

(5) The right to participate in the development and implementation of his or her person-centered plan of care, including but not limited to:

(i) The right to participate in the planning process, including the right to identify individuals or roles to be included in the planning process, the right to request meetings, and the right to request revisions to the person-centered plan of care.

(ii) The right to participate in establishing the expected goals and outcomes of care, the type, amount, frequency, and duration of care, and any other factors related to the effectiveness of the plan of care.

(iii) The right to be informed, in advance, of changes to the plan of care.

(iv) The right to receive the services and/or items included in the plan of care.

(v) The right to see the care plan, including the right to sign after changes to the plan of care.

(6) The right to self-administer medications if the interdisciplinary team has determined that this practice is clinically appropriate in accordance with § 483.11(b)(2).

(7) Nothing in this paragraph should be construed as the right of the resident to receive the provision of medical treatment or medical services deemed medically unnecessary or inappropriate.

(c) Choice of attending physician. The resident has the right to choose his or her attending physician.

(1) The physician must be licensed to practice, and

(2) The physician must meet the professional credentialing requirements of the facility.

(3) If the physician chosen by the resident refuses to or does not meet requirements specified in this part, the facility may seek alternate physician participation as specified in § 483.11(c) to assure provision of appropriate and adequate care and treatment.

(d) Respect and dignity. The resident has a right to be treated with respect and dignity, including:

(1) The right to be free from any physical or chemical restraints imposed for purposes of discipline or convenience, and not required to treat the resident's medical symptoms.

(2) The right to retain and use personal possessions, including furnishings, and clothing, as space
permits, unless to do so would infringe upon the rights or health and safety of other residents. (3) The right to reside and receive services in the facility with reasonable accommodation of resident needs and preferences except when to do so would endanger the health or safety of the resident or other residents. (4) The right to share a room with his or her spouse when married residents live in the same facility and both spouses consent to the arrangement. (5) The right to share a room with his or her roommate of choice when practicable, when both residents live in the same facility and both residents consent to the arrangement. (6) The right to receive notice before the resident’s room or roommate in the facility is changed. (7) The right to refuse to transfer to another room in the facility, if the purpose of the transfer is to relocate: (i) A resident from a SNF from the distinct part of the institution that is a SNF to a part of the institution that is not a SNF, or (ii) A resident of a NF from the distinct part of the institution that is a NF to a distinct part of the institution that is a SNF. (8) A resident’s exercise of the right to refuse transfer does not affect the resident’s eligibility or entitlement to Medicare or Medicaid benefits. (a) Self-determination. The resident has the right to self-determination, including but not limited to the right to determine: (1) Choose activities, schedules (including sleeping and waking times), health care and providers of health care services consistent with his or her interests, assessments, and plan of care; (2) Interact with members of the community and participate in community activities both inside and outside the facility; (3) Receive visitors of his or her choosing at the time of his or her choosing, subject to the resident’s right to deny visitation, and in a manner that does not impose on the rights of another resident, including the individuals specified in § 483.15(d); (4) Organize and participate in resident groups in the facility; (5) Participate in family groups; (6) Have family member(s) or other resident representative(s) meet in the facility with the families or resident representative(s) of other residents in the facility; (7) Participate in other activities, including social, religious, and community activities that do not interfere with the rights of other residents in the facility; (8) Choose or refuse to perform services for the facility subject to the facility requirements in § 483.11(d)(4); (9) Manage his or her financial affairs. This includes the right to know, in advance, what charges a facility may impose against a resident’s personal funds as specified in § 483.31(d)(6)(i)(i); (10) Make comments about aspects of his or her life in the facility that are significant to the resident. (f) Access to information. (1) The resident has the right to be informed of his or her rights and of all rules and regulations governing resident conduct and responsibilities during his or her stay in the facility. (2) The resident has the right to receive notices verbally (meaning spoken) and in writing (including Braille) in a format and a language he or she understands, including (i) Required notices as specified in § 483.11(e)(ii); (ii) Information and contact information for State and local advocacy organizations, including but not limited to the State Long-Term Care Ombudsman program (established under section 712 of the Older Americans Act of 1965, as amended 2006 (42 U. S. C. 3001 et seq) and the protection and advocacy system (as designated by the state, and as established under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (42 U.S.C. 15001 et seq); (iii) Information regarding Medicare and Medicaid eligibility and coverage; (iv) Contact information for the Aging and Disability Resource Center (established under Section 202(a)(20)(B)(iii) of the Older Americans Act); or other No Wrong Door Program (v) Contact information for the Medicaid fraud control unit; and (vi) Information for filing grievances or complaints about abuse, neglect, misappropriation of resident property in the facility, and non-compliance with § 489.102 of this chapter. (3) The resident has the right to access medical records pertaining to him or herself: (i) Upon an oral or written request, in the form and format requested by the individual, if it is readily producible in such form and format (including in an electronic form or format when such medical records are maintained electronically); or, if not, in a readable hard copy form or such other form and format as agreed to by the facility and the individual, including current medical records, within 24 hours (excluding weekends and holidays); and (ii) After receipt of his or her medical records for inspection, to purchase, a copy of the medical records or any portions thereof (including in an electronic form or format when such medical records are maintained electronically) upon request and 2 working days advance notice to the facility. The facility may impose a reasonable, cost-based fee on the provision of copies, provided that the fee includes only the cost of: (A) Labor for copying the medical records requested by the individual, whether in paper or electronic form; (B) Supplies for creating the paper copy or electronic media if the individual requests that the electronic copy be provided on portable media; and (C) Postage, when the individual has requested the copy be mailed. (4) The resident has the right to—(1) Examine the results of the most recent survey of the facility conducted by Federal or State surveyors and any plan of correction in effect with respect to the facility; and (ii) Receive information from agencies acting as client advocates, and be afforded the opportunity to contact these agencies. (g) Privacy and confidentiality. The resident has a right to personal privacy and confidentiality of his or her personal and medical records. (1) This includes the right to privacy in his or her verbal (that is, spoken), written, and electronic communications, including the right to send and receive unopened mail and other letters, packages and other materials delivered to the facility for the resident, including those delivered through a means other than a postal service. (2) Personal privacy includes accommodations, medical treatment, written and telephone communications, personal care, visits, and meetings of family and resident groups, but this does not require the facility to provide a private room for each resident; (3) The resident has a right to a secure and confidential medical record. (4) The resident has the right to refuse the release of personal and medical records except as provided at § 483.70(1)(2) or other applicable federal or state laws. (h) Communication. (1) The resident has the right to have reasonable access to the use of a telephone, including TTY and TDD services, and a place in the facility where calls can be made without being overheard. This includes the right to retain and use a cellular phone at the resident’s own expense. (2) The resident has the right to have reasonable access to and privacy in their use of electronic communications such
as email and video communications and for Internet research.

(i) If the access is available to the facility.

(ii) At the resident's expense, if any additional expense is incurred by the facility to provide such access to the resident.

(b) The resident has the right to send and receive mail, and to receive letters, packages, and other materials delivered to the facility for the resident through a means other than a postal service, including the right to:

(i) Privacy of such communications consistent with paragraph (g)(1) of this section; and

(ii) Access to stationery, postage, and writing implements at the resident's own expense.

(c) Safe environment. The resident has a right to a safe, clean, comfortable and healthful environment in accordance with §483.11(g), including but not limited to receiving treatment and supports for daily living safely.

(d) Grievances. (1) The resident has the right to voice grievances to the facility or other agency or entity that hears grievances without discrimination or reprisal and without fear of discrimination or reprisal. Such grievances include those with respect to care and treatment which has been furnished as well as that which has not been furnished.

(2) The resident has the right to prompt efforts by the facility to resolve grievances in accordance with §483.11(h).

(e) Attending physician. (1) The facility must ensure that each resident remains informed of the name, specialty, and way of contacting the attending physician and other primary care professionals responsible for his or her care.

(2) The facility must inform the resident if the facility determines that the attending physician chosen by the resident is unable or unwilling to meet requirements specified in this part and the facility seeks alternate physician participation to assure provision of appropriate and adequate care and treatment. The facility must discuss the alternative physician participation with the resident and honor the resident's preferences, if any, among options.

(f) Exercise of rights. (1) The facility must ensure that the resident can exercise his or her rights without interference, coercion, discrimination, or reprisal from the facility.

(2) The facility must provide equal access to quality care regardless of diagnosis, severity of condition, or payment source. A facility must establish and maintain identical policies and practices regarding transfer, discharge, and the provision of services under the State plan for all residents regardless of payment source.

(3) The facility must treat the decisions of a resident representative as the decisions of the resident to the extent required by the court or delegated by the resident, in accordance with applicable law.

(4) The facility shall not extend the resident representative the right to make decisions on behalf of the resident beyond the extent required by the court or delegated by the resident, in accordance with applicable law.

(5) If the facility has reason to believe that a resident representative is making decisions or taking actions that are not in the best interests of a resident, the facility may report such concerns as permitted and shall report such concerns when and in the manner required under State law.

(g) Planning and implementing care. (1) The facility shall inform the resident of the right to participate in his or her treatment and shall support the resident in this right, consistent with §483.10(b).

(2) The interdisciplinary team, as defined by §483.22(b)(2)(ii), is responsible for determining if resident self-administration of medications is clinically appropriate.

(h) Facility responsibilities. A facility must treat each resident with respect and dignity and care for each resident in a manner and in an environment that promotes maintenance or enhancement of his or her quality of life, recognizing each resident's individuality. The facility must protect and promote the rights of the resident as specified in §483.10, including, but not limited to the following obligations:

(a) Exercise of rights. (1) The facility must ensure that the resident can exercise his or her rights without interference, coercion, discrimination, or reprisal from the facility.

(b) Exercise of rights. (2) The facility must provide equal access to quality care regardless of diagnosis, severity of condition, or payment source. A facility must establish and maintain identical policies and practices regarding transfer, discharge, and the provision of services under the State plan for all residents regardless of payment source.

(c) Exercise of rights. (3) The facility must treat the decisions of a resident representative as the decisions of the resident to the extent required by the court or delegated by the resident, in accordance with applicable law.

(d) Exercise of rights. (4) The facility shall not extend the resident representative the right to make decisions on behalf of the resident beyond the extent required by the court or delegated by the resident, in accordance with applicable law.

(e) Planning and implementing care. (1) The facility shall inform the resident of the right to participate in his or her treatment and shall support the resident in this right, consistent with §483.10(b).

(2) The interdisciplinary team, as defined by §483.22(b)(2)(ii), is responsible for determining if resident self-administration of medications is clinically appropriate.

(f) Facility responsibilities. (1) The facility must ensure that each resident remains informed of the name, specialty, and way of contacting the attending physician and other primary care professionals responsible for his or her care.

(2) The facility must inform the resident if the facility determines that the attending physician chosen by the resident is unable or unwilling to meet requirements specified in this part and the facility seeks alternate physician participation to assure provision of appropriate and adequate care and treatment. The facility must discuss the alternative physician participation with the resident and honor the resident's preferences, if any, among options.

(g) Exercise of rights. (3) The facility must ensure that the resident can exercise his or her rights without interference, coercion, discrimination, or reprisal from the facility.

(h) Exercise of rights. (4) The facility shall not extend the resident representative the right to make decisions on behalf of the resident beyond the extent required by the court or delegated by the resident, in accordance with applicable law.
(B) Each covered individual shall report not later than 2 hours after forming the suspicion, if the events that cause the suspicion occur in serious bodily injury, or not later than 24 hours if the events that cause the suspicion do not result in serious bodily injury.

(ii) Posting a conspicuous notice of employee rights, as defined at section 1150B(d)(3) of the Act.

(iii) Prohibiting and preventing retaliation, as defined at section 1150B(d)(1) and (2) of the Act.

(c) In response to allegations of abuse, neglect, exploitation, or mistreatment, the facility must:

(1) Ensure that all alleged violations involving abuse, neglect, exploitation or mistreatment, including injuries of unknown source and misappropriation of resident property, are reported immediately to the administrator of the facility and to other officials (including to the State survey and certification agency and adult protective services where state law provides for jurisdiction in long-term care facilities) in accordance with State law through established procedures.

(2) Have evidence that all alleged violations are thoroughly investigated.

(3) Prevent further potential abuse, neglect, exploitation, or mistreatment while the investigation is in progress.

(4) Report the results of all investigations to the administrator or his resident representative and to other officials in accordance with State law (including to the State survey and certification agency) within 5 working days of the incident, and if the alleged violation is verified appropriate corrective action must be taken.

§483.13 [Removed]


17. Section 483.15 is revised to read as follows:

§483.15 Transitions of care.

Transitions of care include admissions to and discharges from or to a SNF or NF. This section also addresses bed-hold policies and therapeutic leaves.

(a) Admissions policy. (1) The facility must—

(i) Not request or require residents or potential residents to waive their rights as set forth in this part and in applicable State, Federal or local licensing or certification laws, including but not limited to their rights to Medicare or Medicaid; and

(ii) Not request or require oral or written assurance that residents or potential residents are not eligible for, or will not apply for, Medicare or Medicaid benefits.

(2) The facility must—

(i) Not request or require residents or potential residents to waive potential facility liability for losses of personal property.

(3) The facility must not request or require a third party guarantee of payment to the facility as a condition of admission or expedited admission, or continued stay in the facility. However, the facility may require and make available to pay for facility care to sign a contract, without incurring personal financial liability, to provide facility payment from the resident's income or resources available to pay for facility care.

(4) In the case of a person eligible for Medicaid, a nursing facility may not charge, solicit, accept, or receive, in addition to the amount otherwise required to be paid under the State plan, any gift, money, donation, or other consideration as a precondition of admission, expedited admission or continued stay in the facility.

However,—

(i) A nursing facility may charge a resident who is eligible for Medicaid for items and services the resident has requested and received, and that are not specified in the State plan as included in the term “nursing facility services” so long as the facility gives proper notice of the availability and cost of these services to residents and does not condition the resident's admission or continued stay on the request for and receipt of such additional services; and

(ii) A nursing facility may solicit, accept, or receive a charitable, religious, or philanthropic contribution from an organization or from a person unrelated to a Medicaid eligible resident or potential resident, but to the extent that the contribution is not a condition of admission, expedited admission, or continued stay in the facility for a Medicaid eligible resident.

(5) States or political subdivisions may apply stricter admissions standards under State or local laws than are specified in this section, to prohibit discrimination against individuals entitled to Medicaid.

(6) A nursing facility must disclose and provide to a resident or potential resident, at or prior to time of admission, notice of special characteristics or service limitations of the facility.

(7) A nursing facility that is a composite distinct part as defined in §483.5(c) must disclose in its admission agreement its physical configuration, including the various locations that comprise the composite distinct part, and must specify the policies that apply to room changes between its different locations under paragraph (b)(10) of this section.

(b) Transfer and discharge—(1) Facility requirements—(1)(i) Equal access to quality care. (A) A facility must establish, maintain and implement identical policies and practices regarding transfer, discharge, and the provision of services for all individuals regardless of source of payment; (B) The facility may charge any amount for services furnished to non-Medicaid residents unless otherwise limited by state law and consistent with the notice requirement in §483.11(e)(11)(i) and (e)(12) describing the charges; and (C) The State is not required to offer additional services on behalf of a resident other than services provided in the State plan.

(ii) The facility must permit each resident to remain in the facility, and not transfer or discharge the resident from the facility unless—

(A) The transfer or discharge is necessary for the resident's welfare and the resident's needs cannot be met in the facility; (B) The transfer or discharge is appropriate because the resident's health has improved sufficiently so the resident no longer needs the services provided by the facility; (C) The safety of individuals in the facility is endangered due to the clinical or behavioral status of the resident; (D) The health of individuals in the facility would otherwise be endangered; (E) The resident has failed, after reasonable and appropriate notice, to pay for (or to have paid under Medicare or Medicaid) a stay at the facility. Non-payment does not apply unless the resident does not submit the necessary paperwork for third party payment or until the third party, including Medicare or Medicaid, denies the claim and the resident refuses to pay for his or her stay. For a resident who becomes eligible for Medicaid after admission to a facility, the facility may discharge a resident only allowable charges under Medicaid; or (F) The facility ceases to operate.

(iii) The facility may not transfer or discharge the resident while the appeal is pending, pursuant to §431.230 of this chapter, when a resident exercises his or her right to appeal a transfer or discharge notice from the facility pursuant to §431.220(a)(3) of this chapter.

(2) Documentation. When the facility transfers or discharges a resident under any of the circumstances specified in paragraphs (b)(1)(i)(A) through (F) of
this section, the facility must ensure that the transfer or discharge is documented in the resident’s clinical record and appropriate information is communicated to the receiving health care institution or provider.

(i) Documentation in the resident’s clinical record must include:

(A) The basis for the transfer per paragraph (b)(1)(i)(l).

(B) In the case of paragraph (b)(1)(i)(ii) of this section, the specific resident need(s) that cannot be met, facility attempts to meet the resident needs, and the service available at the receiving facility to meet the need(s).

(ii) The documentation must be made by—

(A) The resident’s physician when transfer or discharge is necessary under paragraph (b)(1)(i)(A) or (B) of this section, and

(B) A physician when transfer or discharge is necessary under paragraph (b)(1)(i)(C) or (D) of this section.

(iii) Information provided to the receiving provider must include a minimum of the following:

(A) Demographic information including but not limited to name, sex, date of birth, race, ethnicity, and preferred language.

(B) Resident representative information including contact information.

(C) Advance Directive information.

(D) History of present illness/cause for transfer including primary care team contact information.

(E) Past medical/surgical history including procedures.

(F) Active diagnoses/Current problem list and status.

(G) Laboratory tests and the results of pertinent laboratory and other diagnostic testing.

(H) Functional status.

(I) Psychosocial assessment, including cognitive status.

(J) Social Supports

(K) Behavioral Health Issues

(L) Medications.

(M) Allergies, including medication allergies.

(N) Immunizations.

(O) Smoking status.

(P) Vital signs.

(Q) Unique device identifier(s) for a patient’s implantable device(s), if any.

(R) Comprehensive care plan goals, including health concerns, assessment and plan, resident preferences, interventions, including efforts to meet resident needs, and resident status.

(iv) This requirement may be satisfied by the discharge summary providing it meets the requirements of §483.21(c) and includes at a minimum the information specified in paragraph (b)(2)(iii) of this section.

(3) Notice before transfer. Before a facility transfers or discharges a resident, the facility must—

(i) Notify the resident and the resident’s representative(s) of the transfer or discharge and the reasons for the move in writing and in a language and manner they understand. Subject to the resident’s agreement, the facility must send a copy of the notice to a representative of the Office of the State Long-Term Care Ombudsman.

(ii) Record the reasons for the transfer or discharge in the resident’s clinical record in accordance with paragraph (b)(2) of this section; and

(iii) Include in the notice the items described in paragraph (b)(5) of this section.

(4) Timing of the notice. (i) Except as specified in paragraphs (b)(4)(ii) and (b)(5) of this section, the notice of transfer or discharge required under this section must be made by the facility at least 30 days before the resident is transferred or discharged.

(ii) Notice must be made as soon as practicable before transfer or discharge when—

(A) The safety of individuals in the facility would be endangered under paragraph (b)(1)(i)(C) of this section;

(B) The health of individuals in the facility would be endangered, under paragraph (b)(1)(i)(D) of this section;

(C) The resident’s health improves sufficiently to allow a more immediate transfer or discharge, under paragraph (b)(1)(i)(B) of this section;

(D) An immediate transfer or discharge is required by the resident’s urgent medical needs, under paragraph (b)(1)(i)(A) of this section, or

(E) A resident or person residing in the facility for 30 days.

(5) Contents of the notice. The written notice specified in paragraph (b)(3) of this section must include the following:

(i) The reason for transfer or discharge;

(ii) The effective date of transfer or discharge;

(iii) The location to which the resident is expected to be transferred or discharged;

(iv) A statement that the resident has the right to appeal the action to the State, the name, address (mailing and email), and telephone number of the State entity which receives such requests; and information on how to obtain an appeal form and assistance in completing the form and submitting the appeal hearing request;

(v) The resident’s name, address (mailing and email) and telephone number of the Office of the State Long-Term Care Ombudsman;

(vi) For nursing facility residents with intellectual and developmental disabilities, the mailing and email address and telephone number of the agency responsible for the protection and advocacy of individuals with developmental disabilities established under Part C of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (42 U.S.C. 10802); and

(vii) For nursing facility residents with mental illness, the mailing and email address and telephone number of the agency responsible for the protection and advocacy of individuals with mental illness established under the Protection and Advocacy for Mentally Ill Individuals Act.

(6) Changes to the notice. If the information in the notice changes prior to effecting the transfer or discharge, the facility must update the recipients of the notice as soon as practicable once the updated information becomes available.

(7) Orientation for transfer or discharge. A facility must provide and document sufficient preparation and orientation to residents to ensure safe and orderly transfer or discharge from the facility. This orientation must be provided in a form and manner that the resident can understand.

(8) Notice in advance of facility closure. In the case of facility closure, the individual who is the administrator of the facility must provide written notification prior to the impending closure to the State Survey Agency, the Office of the State Long-Term Care Ombudsman, residents of the facility, and the resident representatives of the residents or other responsible parties, as well as the plan for the transfer and adequate relocation of the residents, as required at §483.70(s).

(9) Room changes a composite distinct part. Room changes in a facility that is a composite distinct part (as defined in §483.3) are subject to the requirements of §483.30(d)(7) and must be limited to moves within the particular building in which the resident resides, unless the resident voluntarily agrees to move to another of the composite distinct part’s locations.

(a) Notice of bed-hold policy and readmission—(1) Notice before transfer. Before a nursing facility transfers a resident to a hospital or the resident goes on therapeutic leave, the nursing facility must provide written information to the resident or resident representative that specifies—

(i) The duration of the state bed-hold policy, if any, during which the resident is permitted to return and resume residence in the nursing facility;

(ii) The Reserve bed payment policy in the state plan, under §447.40 of this chapter, if any;
CMCS Informational Bulletin

DATE: July 7, 2014

FROM: Cindy Mann, Director
Center for Medicaid and CHIP Services

SUBJECT: Clarification of Medicaid Coverage of Services to Children with Autism

In response to increased interest and activity with respect to services available to children with autism spectrum disorder (ASD), CMS is providing information on approaches available under the federal Medicaid program for providing services to eligible individuals with ASD.

Background

Autism spectrum disorder is a developmental disability that can cause significant social, communication and behavioral challenges. A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called autism spectrum disorder. Currently, the Center for Disease Control and Prevention (CDC) estimates that approximately 1 in 68 children has been identified with ASD. 1

Treatments for children with ASD can improve physical and mental development. Generally these treatments can be categorized in four categories: 1) behavioral and communication approaches; 2) dietary approaches; 3) medications; and 4) complementary and alternative medicine. 2 While much of the current national discussion focuses on one particular treatment modality called Applied Behavioral Analysis (ABA), there are other recognized and emerging treatment modalities for children with ASD, including those described in the ASD Services, Final Report on Environmental Scan (see link below) 3. This bulletin provides information related to services available to individuals with ASD through the federal Medicaid program.

The federal Medicaid program may reimburse for services to address ASD through a variety of authorities. Services can be reimbursed through section 1905(a) of the Social Security Act (the Act), section 1915(i) state plan Home and Community-Based Services, section 1915(c) Home

1 http://www.cdc.gov/ncbddd/autism/facts.html
2 http://www.cdc.gov/ncbddd/autism/treatment.html
3 http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/Autism-Spectrum-Disorders.pdf
and Community-Based Services (HCBS) waiver programs and section 1115 research and demonstration programs.

**State Plan Authorities**

Under the Medicaid state plan, services to address ASD may be covered under several different section 1905(a) benefit categories. Those categories include: section 1905(a)(6) - services of other licensed practitioners; section 1905(a)(13)(c) - preventive services; and section 1905(a)(10) - therapy services. States electing these services may need to update the Medicaid state plan in order to ensure federal financial participation (FFP) is available for expenditures for these services. In addition, for children, as discussed below, states must cover services that could otherwise be covered at state option under these categories consistent with the provisions at 1905(a)(4)(B) for Early and Periodic Screening, Diagnostic and Treatment services (EPSDT). Below is information on these coverage categories for services to address ASD. Under these section 1905(a) benefit categories all other state Medicaid plan requirements such state-wideness and comparability must also be met.

**Other Licensed Practitioner Services**

Other Licensed Practitioner services (OLP) services, defined at 42 CFR 440.60, are “medical or remedial care or services, other than physicians’ services, provided by licensed practitioners within the scope of practice as defined under State law.” If a state licenses practitioners who furnish services to address ASD, the state may elect to cover those providers under this section of their state plan even if the providers are not covered under other sections of the plan (e.g., physical therapist, occupational therapist, etc.). A state would need to submit a state plan amendment (SPA) to add the new licensed provider to their Medicaid plan. The SPA must describe the provider’s qualifications and include a reimbursement methodology for paying the provider.

In addition, services that are furnished by non-licensed practitioners under the supervision of a licensed practitioner could be covered under the OLP benefit if the criteria below are met:

- Services are furnished directly by non-licensed practitioners who work under the supervision of the licensed practitioners;
- The licensed provider is able to furnish the service being provided;
- The state’s Scope of Practice Act for the licensed practitioners specifically allows the licensed practitioners to supervise the non-licensed practitioners who furnish the service;
- The state’s Scope of Practice Act also requires the licensed practitioners to assume professional responsibility for the patient and the service furnished by the unlicensed practitioner under their supervision; and
- The licensed practitioners bill for the service;

**Preventive Services**

Preventive Services, defined at 42 CFR 440.130(c) are “services recommended by a physician or other licensed practitioner of the healing arts within the scope of his practice under state law to—

1. Prevent disease, disability, and other health conditions or their progression;
2. Prolong life; and
3. Promote physical and mental health and efficiency”
A regulatory change that took effect January 1, 2014, permits coverage of preventive services furnished by non-licensed practitioners who meet the qualifications set by the state, to furnish services under this state plan benefit as long as the services are recommended by a physician or other licensed practitioner. Under the preventive services benefit, in the state plan, the state must 1) list the services to be provided to ensure that services meet the definition of preventive services as stated in section 4385 of the State Medicaid Manual (including the requirement for the service to involve direct patient care); 2) identify the type(s) of non-licensed practitioners who may furnish the services; and 3) include a summary of the state’s provider qualifications that make these practitioners qualified to furnish the services, including any required education, training, experience, credentialing, supervision, oversight and/or registration.

Therapy Services
Physical therapy, occupational therapy and services for individuals with speech, hearing and language disorders, may be covered under the Medicaid therapies benefit at 42 CFR 440.110. Physical and occupational therapy must be prescribed by a physician or other licensed practitioner of the healing arts within the scope of his/her practice under state law and provided to a beneficiary by or under the direction of a qualified therapist. Services for individuals with speech, hearing and language disorders mean diagnostic, screening, preventive or corrective services provided by or under the direction of a speech pathologist or audiologist, for which a patient is referred by a physician or other licensed practitioner of the healing arts within the scope of his or her practice under state law.

States would need to include an assurance in the state plan that the state furnishes the therapy in accordance with 42 CFR 440.110. States would also need to describe the supervisory arrangements if a practitioner is furnishing the therapy under the direction of a qualified therapist. Finally, for audiology services, the state plan must reflect the supervision requirements as set forth at 42 CFR 440.110(c)(3).

Section 1915(i) of the Social Security Act
States can offer a variety of services under a section 1915(i) state plan Home and Community-Based Services (HCBS) benefit. The benefit may be targeted to one or more specific populations including individuals with ASD and can provide services and supports above and beyond those included in section 1905(a). Participants must meet state-defined criteria based on need and typically receive a combination of acute-care medical services (like dental services, skilled nursing services) and other long-term services such as respite care, supported employment, habilitative supports, and environmental modifications.

Other Medicaid Authorities

There are several other Medicaid authorities that may be used to provide services to address ASD. Below is a discussion of each of those authorities:

Section 1915(c) of the Social Security Act
The section 1915(c) Home and Community-Based Services waiver program allows states to provide a combination of medical services and long-term services and supports. Services include
but are not limited to adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community. Participants must meet an institutional level of care but are served in the community. Section 1915(c) waiver programs also require that services be furnished in home and community-based settings. For individuals under the age of 21 who are eligible for EPSDT services, an HCBS waiver could provide services and supports for ASD that are above and beyond services listed in section 1905(a), such as respite care. Additionally, for individuals who are receiving state plan benefits as part of EPSDT that are not available to adults under the state plan, waiver services may be used to help these individuals transition into adulthood and not lose valuable necessary services and supports.

Section 1115 Research and Demonstration Waiver
Section 1115 of the Act provides the Secretary of the Department of Health and Human Services broad authority to authorize experimental, pilot, or demonstration programs that promote the objectives of the Medicaid program. Flexibility under section 1115 is sufficiently broad to allow States to test substantially new ideas, including benefit design or delivery system reform, of policy merit. The Secretary can approve an 1115 demonstration for up to five years, and states may submit extension requests to continue the program for additional periods of time. Demonstrations must be "budget neutral" over the life of the program, meaning they cannot be expected to cost the Federal government more than it would cost without the demonstration.

EPSDT Benefit Requirements

Section 1905(r) of the Act defines the EPSDT benefit to include a comprehensive array of preventive, diagnostic, and treatment services for low-income infants, children, and adolescents under age 21. States are required to arrange for and cover for individuals eligible for the EPSDT benefit any Medicaid coverable service listed in section 1905(a) of the Act that is determined to be medically necessary to correct or ameliorate any physical or behavioral conditions. The EPSDT benefit is more robust than the Medicaid benefit package required for adults and is designed to assure that children receive early detection and preventive care, in addition to medically necessary treatment services, so that health problems are averted or diagnosed and treated as early as possible. All children, including children with ASD, must receive EPSDT screenings designed to identify health and developmental issues, including ASD, as early as possible. Good clinical practice requires ruling out any additional medical issues and not assuming that a behavioral manifestation is always attributable to the ASD. EPSDT also requires medically necessary diagnostic and treatment services. When a screening examination indicates the need for further evaluation of a child's health, the child should be appropriately referred for diagnosis and treatment without delay. Ultimately, the goal of EPSDT is to assure that children get the health care they need, when they need it – the right care to the right child at the right time in the right setting.

The role of states is to make sure all covered services are available as well as to assure that families of enrolled children, including children with ASD, are aware of and have access to a broad range of services to meet the individual child's needs; that is, all services that can be covered under section 1905(a), including licensed practitioners' services; speech, occupational,
and physical therapies; physician services; private duty nursing; personal care services; home health, medical equipment and supplies; rehabilitative services; and vision, hearing, and dental services.

If a service, supply or equipment that has been determined to be medically necessary for a child is not listed as covered (for adults) in a state’s Medicaid State Plan, the state will nonetheless need to arrange for and cover it for the child as long as the service or supply is included within the categories of mandatory and optional services listed in section 1905(a) of the Social Security Act. This longstanding coverage design is intended to ensure a comprehensive, high-quality health care benefit for eligible individuals under age 21, including for those with ASD, based on individual determinations of medical necessity.

Implications for Existing Section 1915(c), Section 1915 (i) and Section 1115 Programs

In states with existing 1915(c) waivers that provide services to address ASD, this 1905(a) policy clarification may impact on an individual’s eligibility for the waiver. Waiver services are separated into two categories: waiver services and extended state plan services. Extended state plan services related to section 1905(a) services are not available to individuals under the age of 21 (individuals eligible for EPSDT) because of the expectation that EPSDT will meet the individual’s needs. There are therefore a limited number of services that can be provided to this age group under 1915 (c) waivers, primarily respite, and/or environmental/vehicle modifications.

For states that currently provide waiver services to individuals under age 21 to address ASD, the ability to provide services under the 1905(a) state plan may have the effect of making these individuals ineligible for the waiver unless another waiver service is provided. This implication is especially important for individuals with ASD who may not otherwise be eligible for Medicaid absent the (c) waiver. States need to ensure that these individuals are receiving a waiver service, not coverable under section 1905(a), to ensure that they do not lose access to all Medicaid services by losing waiver eligibility. Individuals age 21 and older may continue to receive services to address ASD through the waiver if a state does not elect to provide these services to adults under its Medicaid state plan.

The same issues arise for children under the 1915(i) authority, which allows for services above and beyond section 1905(a) to be provided under the state plan. CMS is available to provide technical assistance to states that currently have approved waivers or state plans that may be impacted by this clarification. Similarly, states with existing 1115 demonstrations authorizing reimbursement for services provided to children with autism should contact CMS to ensure that EPSDT requirements are met.

We hope this information is helpful. If you have questions please send them to AutismServicesQuestions@cms.hhs.gov.
CMS Issues Clarification of Medicaid Coverage of Services to Children With Autism

(July 17, 2014) Centers for Medicare & Medicaid Services officials released federal guidance for states on Medicaid coverage of therapies for autism, and that guidance indicates such treatments are covered for beneficiaries under age 21. While the guidance focuses on the provision of applied behavior analysis (ABA) therapy, it also acknowledges other treatments.

The Center for Medicaid and CHIP (Children's Health Insurance Plan) Services, a division of CMS, released an informational bulletin to clarify Medicaid coverage of services to children with autism. The bulletin was issued in response to increased interest in this topic—specifically, the provision of ABA therapy. Although the bulletin was written to address services for children with autism under the Medicaid program, it also serves to clarify services that speech-language pathologists and audiologists may provide to individuals diagnosed with other conditions.

Melissa Harris, director, Division of Benefits and Coverage, Disabled and Elderly Health Program Group at CMS, addressed the meeting of the Interagency Autism Coordinating Committee (IACC) regarding this bulletin and emphasized that Medicaid covers ABA and similar services for children with autism. Ms. Harris noted that Medicaid and programs such as Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit requirements do not name a specific treatment, but instead address the service needs of the individual. As noted in the bulletin, "the goal of EPSDT is to assure that children get the health care they need, when they need it—the right care to the right child at the right time in the right setting." For children, states must cover services consistent with the EPSDT provision. Ms. Harris also discussed the application of habilitative and rehabilitative services as defined in the Affordable Care Act (ACA) as extended to the Medicaid population and reminded the group of the definitions of those services as developed by the National Association of Insurance Commissioners (NAIC).

The bulletin outlines four major categories of treatment that are beneficial for children with autism spectrum disorder (ASD)—specifically, services available to individuals with ASD through the federal Medicaid program. The categories are (1) behavioral and communication approaches, (2) dietary approaches, (3) medications, and (4) complementary and alternative medicine. ABA therapy is recognized as one treatment for the child with autism, but the bulletin also identifies other treatments that are available to the ASD population and to others in need of those services.
Medicaid funding for services to children with ASD and other conditions may be reimbursed through a variety of authorities, such as specific sections of the Social Security Act, including Section 1915(c) Home and Community-Based Services and Section 1115 Waiver and State Plan Authorities. States are required to submit a state plan amendment (SPA) to address how all services are addressed, with inclusion of therapy services covered under the Medicaid therapies benefit at 42 Code of Federal Regulations (CFR) 440.110 as relating to qualified provider, referral, scope of services, and supervision/direction of services.

Background
About 1 in 68 children has been identified with autism spectrum disorder (ASD), according to estimates from Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring (ADDM) Network. The number of individuals with ASD has increased in the past several years, along with interest in associated treatments and resources to cover payment for those services.

Resources
- Clarification of Medicaid Coverage of Services to Children With Autism [PDF]
- Habilitative and Rehabilitative Services Defined [PDF]

For more information, please contact Laurie Alban Havens, ASHA's director of private health plan and Medicaid advocacy, at lalbanhavens@asha.org

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Application for a §1915(c) Home and Community-Based Services Waiver

PURPOSE OF THE HCBS WAIVER PROGRAM

The Medicaid Home and Community-Based Services (HCBS) waiver program is authorized in §1915(c) of the Social Security Act. The program permits a State to furnish an array of home and community-based services that assist Medicaid beneficiaries to live in the community and avoid institutionalization. The State has broad discretion to design its waiver program to address the needs of the waiver’s target population. Waiver services complement and/or supplement the services that are available to participants through the Medicaid State plan and other federal, state and local public programs as well as the supports that families and communities provide.

The Centers for Medicare & Medicaid Services (CMS) recognizes that the design and operational features of a waiver program will vary depending on the specific needs of the target population, the resources available to the State, service delivery system structure, State goals and objectives, and other factors. A State has the latitude to design a waiver program that is cost-effective and employs a variety of service delivery approaches, including participant direction of services.

Request for a Renewal to a §1915(c) Home and Community-Based Services Waiver

1. Major Changes

Describe any significant changes to the approved waiver that are being made in this renewal application:

This is a renewal of the DDDS Waiver that has been in continuous operation since 1987. The DDDS waiver is targeted to individuals with intellectual disabilities and autism spectrum disorder who can no longer live independently or with their family. The waiver includes an array of services and supports designed to enable the individual to live safely in the community and to respect and support their desire to work or engage in other productive activities.

The following changes are being made in this renewal application:

The term "Mental Retardation" has been changed to "Intellectual Developmental Disability" throughout the document.

Appendix A

* Performance measure A-3: Number and percent of performance reports reviewed by the Medicaid agency was deleted.
* DDDS felt that this measure was redundant of PM A-5: Number and percent of DMMA/DDDS Quarterly Waiver Mandatory meetings during which the waiver quality assurance and quality improvement activities are discussed."
* Performance measure "A-1: Number and percent of waiver policies approved by the Medicaid agency prior to implementation" was deleted.

Appendix B

* Minimum waiver eligibility age changed from four (4) years to twelve (12) years of age. There were only three clients under the age of 12 who have ever received a waiver service under any of the previous renewals. These clients were all eligible for SSI prior to their enrollment in the DDDS waiver.
* Qualifications for who may perform a Level of Care initial certification and recertification were changed from a physician and a psychologist, respectively, to a QIPD for both the initial and certifications
* The minimum requirement for waiver services received per month was reduced from two (2) to one (1) because case management is no longer claimed as a waiver service
* Per the CMS Crosswalk of Current vs Revised Assurances, sub-assurance B-b-1, LOC annual reevaluations completed within 365 days of previous determination was deleted. DDDS will no longer report on this measure in the annual 372 report but will continue to track it

Appendix C

* Supported Living was added as a new waiver service under “Other”.
* Clinical Consultation: Behavioral and Nursing was broken out into two different waiver services. In the previous version of the application, these two distinct services were combined into a single service category with different provider types

○ 3 years ☑ 5 years

Original Base Waiver Number: DE.0009
Draft ID: DE.08.07.00
D. Type of Waiver (select only one):
   ☑ Regular Waiver
E. Proposed Effective Date: (mm/dd/yy)
   07/01/14

1. Request Information (2 of 3)

F. Level(s) of Care. This waiver is requested in order to provide home and community-based waiver services to individuals who, but for the provision of such services, would require the following level(s) of care, the costs of which would be reimbursed under the approved Medicaid State plan (check each that applies):
   □ Hospital
      Select applicable level of care
      ○ Hospital as defined in 42 CFR §440.10
         If applicable, specify whether the State additionally limits the waiver to subcategories of the hospital level of care:
   ○ Inpatient psychiatric facility for individuals age 21 and under as provided in 42 CFR §440.160
   □ Nursing Facility
      Select applicable level of care
      ○ Nursing Facility As defined in 42 CFR §440.40 and 42 CFR §440.155
         If applicable, specify whether the State additionally limits the waiver to subcategories of the nursing facility level of care:
   ○ Institution for Mental Disease for persons with mental illnesses aged 65 and older as provided in 42 CFR §440.140
   ☑ Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) (as defined in 42 CFR §440.150)
      If applicable, specify whether the State additionally limits the waiver to subcategories of the ICF/IID level of care:

1. Request Information (3 of 3)

G. Concurrent Operation with Other Programs. This waiver operates concurrently with another program (or programs) approved under the following authorities
   Select one:
      ☑ Not applicable
      □ Applicable
         Check the applicable authority or authorities:
         □ Services furnished under the provisions of §1915(a)(1)(a) of the Act and described in Appendix I
         □ Waiver(s) authorized under §1915(b) of the Act.
         Specify the §1915(b) waiver program and indicate whether a §1915(b) waiver application has been submitted or previously approved:
            
         Specify the §1915(b) authorities under which this program operates (check each that applies):

Early and Periodic Screening, Diagnostic, and Treatment

The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. EPSDT is key to ensuring that children and adolescents receive appropriate preventive, dental, mental health, and developmental, and specialty services.

<table>
<thead>
<tr>
<th>Early</th>
<th>Assessing and identifying problems early</th>
</tr>
</thead>
<tbody>
<tr>
<td>Periodic</td>
<td>Checking children's health at periodic, age-appropriate intervals</td>
</tr>
<tr>
<td>Screening</td>
<td>Providing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems</td>
</tr>
<tr>
<td>Diagnostic</td>
<td>Performing diagnostic tests to follow up when a risk is identified, and</td>
</tr>
<tr>
<td>Treatment</td>
<td>Control, correct or reduce health problems found.</td>
</tr>
</tbody>
</table>

EPSDT Services

States are required to provide comprehensive services and furnish all Medicaid coverable, appropriate, and medically necessary services needed to correct and ameliorate health conditions, based on certain federal guidelines. EPSDT is made up of the following screening, diagnostic, and treatment services:

Screening Services

- Comprehensive health and developmental history
- Comprehensive unclothed physical exam
- Appropriate immunizations (according to the Advisory Committee on Immunization Practices)
- Laboratory tests (including lead toxicity screening)
- Health Education (anticipatory guidance including child development, healthy lifestyles, and accident and disease prevention)

Vision Services

At a minimum, diagnosis and treatment for defects in vision, including eyeglasses. Vision services must be provided according to a distinct periodicity schedule developed by the state and at other intervals as medically necessary.

Dental Services

At a minimum, dental services include relief of pain and infections, restoration of teeth, and maintenance of dental health. Dental services may not be limited to emergency services. Each state is required to develop a dental periodicity schedule in consultation with recognized dental organizations involved in child health.
Hearing Services
At a minimum, hearing services include diagnosis and treatment for defects in hearing, including hearing aids.

Other Necessary Health Care Services
States are required to provide any additional health care services that are coverable under the Federal Medicaid program and found to be medically necessary to treat, correct or reduce illnesses and conditions discovered regardless of whether the service is covered in a state's Medicaid plan. It is the responsibility of states to determine medical necessity on a case-by-case basis.

Diagnostic Services
When a screening examination indicates the need for further evaluation of an individual's health, diagnostic services must be provided. Necessary referrals should be made without delay and there should be follow-up to ensure the enrollee receives a complete diagnostic evaluation. States should develop quality assurance procedures to assure that comprehensive care is provided.

Treatment
Necessary health care services must be made available for treatment of all physical and mental illnesses or conditions discovered by any screening and diagnostic procedures.

State Program Guidelines

State Medicaid agencies are required to:

- Inform all Medicaid-eligible individuals under age 21 that EPSDT services are available and of the need for age-appropriate immunizations;
- Provide or arrange for the provision of screening services for all children;
- Arrange (directly or through referral) for corrective treatment as determined by child health screenings; and

Periodicity Schedule

Periodicity schedules for periodic screening, vision, and hearing services must be provided at intervals that meet reasonable standards of medical practice. States must consult with recognized medical organizations involved in child health care in developing their schedules. Alternatively, states may elect to use a nationally recognized pediatric periodicity schedule (i.e., Bright Futures [http://brightfutures.aap.org/index.html]). A separate dental periodicity schedule is also required.

Developmental and Behavioral Screening

Periodic developmental and behavioral screening during early childhood is essential to identify possible delays in growth and development, when steps to address deficits can be most effective. These screenings are required for children enrolled in Medicaid, and are also covered for children enrolled in CHIP. This CMS Fact Sheet (/medicaid-chip-program-information/by-topics/quality-of-care/downloads/cms_fact_sheet_dev_screening.pdf) describes CMS resources to support states in ensuring enrolled children receive these screenings. Birth to 5: Watch Me Thrive (http://www.acf.hhs.gov/programs/ecd/watch-me-thrive), a joint effort between the Department of
Health and Human Services and the Department of Education, provides additional resources to support states, providers and communities to increase developmental and behavioral screening of young children.

Lead Screening

CMS has updated its Medicaid lead screening policy for children eligible for EPSDT services. For more information, see the June 2012 Informational Bulletin (/federal-policy-guidance/downloads/cib-06-22-12.pdf). CMS recognizes that lead poisoning continues to be a problem for a small share of low-income children. To improve screening of children most at risk for lead exposure, CMS is aligning Medicaid lead screening policy with current recommendations of the Centers for Disease Control and Prevention (CDC). The new policy encourages a targeted screening approach in States that have sufficient data to support this action. We have developed materials to assist States with the process of determining their lead screening approach going forward. CMS and CDC have developed guidance and process (/medicaid-chip-program-information/by-topics/benefits/downloads/targetedleadsscreening.pdf) for States that want to request to move to a targeted screening approach. Interested States should send requests and supporting documentation to the EPSDT mailbox at EPSDT@cms.hhs.gov (mailto:EPSDT@cms.hhs.gov), with the subject line: "Request for Use of Targeted Lead Screening."

EPSDT Strategy Guides to Support States with the Medicaid Benefit for Children and Adolescents

In 1967, Congress introduced the Medicaid benefit for children and adolescents, known as Early and Periodic Screening, Diagnostic and Treatment (EPSDT). The goal of this benefit is to ensure that children under the age of 21 who are enrolled in Medicaid receive age-appropriate screening, preventive services, and treatment services that are medically necessary to correct or ameliorate any identified conditions — the right care to the right child at the right time in the right setting. This broad scope supports a comprehensive, high-quality health benefit. States share responsibility for implementing the EPSDT benefit with the Centers for Medicare & Medicaid Services. (For more information, see "What You Need to Know about EPSDT (/medicaid-chip-program-information/by-topics/benefits/downloads/what-you-need-to-know-about-epsdt.pdf)".)

As one outcome of a National EPSDT Improvement Workgroup, the Center for Medicaid & CHIP Services is developing a set of strategy guides, each on a specific topic, to support states and their partners as they implement the EPSDT benefit. Each strategy guide identifies specific, doable approaches to improve access, utilization and quality of care for children and adolescents enrolled in Medicaid. Examples of state successes are offered along with web-based links to resources, tools and more in-depth.

The first four guides in the series are:

- Paving the Road to Good Health: Strategies for Increasing Medicaid Adolescent Well-Care Visits (/medicaid-chip-program-information/by-topics/benefits/downloads/paving-the-road-to-good-health.pdf)

EPSDT Data

The Form CMS-416 (/medicaid-chip-program-information(by-topics/benefits/downloads/form-416.zip) is used by CMS to collect basic information on State Medicaid and CHIP programs to assess the effectiveness of EPSDT. See Form CMS-416 instructions (/medicaid-chip-program-information(by-topics/benefits/downloads/cms-416-instructions.pdf). States must provide CMS with the following information:

1. Number of children provided child health screening services
2. Number of children referred for corrective treatment
3. Number of children receiving dental services
4. State’s results in attaining goals set under section 1905(r) of the Social Security Act.

  • Crosswalk of CPT Codes to CDT Codes (01/22/2015)
  • CMS-416 Final Revised Instructions: Questions and Answers (/medicaid-chip-program-information(by-topics/benefits/downloads/416-faqs.pdf) (02/19/2015)
  • Learn How to Report the CMS 416 Dental Data (/medicaid-chip-program-information(by-topics/benefits/416-dental-reporting-training.html)

• Electronic Form CMS-416 (Excel) (/medicaid-chip-program-information(by-topics/benefits/downloads/form-416.zip). To request a 508-version of the form, please email EPSDT@cms.hhs.gov (mailto:EPSDT@cms.hhs.gov).

• FY 2014 Data (/medicaid-chip-program-information(by-topics/benefits/downloads/fy-2014-epsdt-data.zip) (as of 1/15/16. Now includes data from PR)
• FY 2013 Data (/medicaid-chip-program-information(by-topics/benefits/downloads/fy-2013-epsdt-data.zip) (as of 10/22/14)
• FY 2012 Data (/medicaid-chip-program-information(by-topics/benefits/downloads/fy-2012-epsdt-data.zip) (as of 10/22/14)
• FY 2011 Data (/medicaid-chip-program-information(by-topics/benefits/downloads/fy-2011-epsdt-data.zip) (as of 1/07/14)
• FY 2010 Data (/medicaid-chip-program-information(by-topics/benefits/downloads/fy-2010-epsdt-data.zip) (as of 11/19/14)

National EPSDT Improvement Workgroup

In December 2010, CMS convened a National EPSDT Improvement Workgroup that included state representatives, children’s health providers, consumer representatives, and other experts in the areas of maternal and child health, Medicaid, and data analysis. The members of the group will help CMS identify the most critical areas for improvement of EPSDT. The group, which meets periodically throughout the year, will also discuss steps that the federal government might undertake in partnership
with states and others to both increase the number of children accessing services, and improve the quality of the data reporting that enables a better understanding how effective HHS is putting EPSDT to work for children.

**Benefits Content**

- Autism Services (/medicaid-chip-program-information/by-population/autism-services.html)
- Early Periodic Screening Diagnosis & Treatment (/medicaid-chip-program-information/by-topics/benefits/early-and-periodic-screening-diagnostic-and-treatment.html)
- Dental Care (/medicaid-chip-program-information/by-topics/benefits/dental-care.html)
- Alternative Benefit Plans (/medicaid-chip-program-information/by-topics/benefits/alternative-benefit-plans.html)
- Prescription Drugs (/medicaid-chip-program-information/by-topics/benefits/prescription-drugs/prescription-drugs.html)
- Prevention (/medicaid-chip-program-information/by-topics/benefits/prevention.html)
- Behavioral Health Services (/medicaid-chip-program-information/by-topics/benefits/mental-health-services.html)
- Tobacco Cessation (/medicaid-chip-program-information/by-topics/benefits/tobacco.html)

**Related Resources**

- CMS and State EPSDT Contacts (/medicaid-chip-program-information/by-topics/benefits/downloads/epsdt-contacts.pdf)
- InsureKidsNow.gov (http://www.insurekidsnow.gov/)
- EPSDT Information from the Health Resources & Services Administration (http://mchb.hrsa.gov/epsdt/)
Autism Spectrum Disorders
Prepared by: Abigail Coursolle

Introduction

The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) mandate of the Medicaid Act requires states to cover a wide variety of health services to correct or ameliorate the illnesses or conditions of children under age 21 in Medicaid. As new treatments and services are developed and incorporated into the standard of care for treating children’s illnesses and conditions, the Centers for Medicare & Medicaid Services (CMS) has struggled to ensure that state EPSDT programs keep up with the evolving standard of care for children.

A recent example involves behavioral treatments for Autism Spectrum Disorder (ASD), a developmental disability that can cause significant delays in social, communication, and other behavioral skills. The standard of care for children with ASD for many years has included intensive behavioral interventions such as Applied Behavioral Analysis (ABA) therapy. ABA therapy is based on a one-on-one teaching approach that relies on reinforced practice of various skills. Yet states have been slow to cover these interventions under their Medicaid programs, and CMS had also not required states to cover them until last year. Due in part to NHcLP’s advocacy, in July 2014, CMS issued a Clarification of Medicaid Coverage of Services to Children with Autism (ASD CMS Guidance), which made clear that states must provide evidence-based treatments for children with ASD in Medicaid. This month’s Health Advocate reviews the advocacy history that led up to this guidance, and then examines trends in the states’ implementation of the guidance.

Treatment for Autism Spectrum Disorders

The CDC recently estimated that approximately one in every 68 children has been identified with ASD. (CDC, Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years (2014).) Since the 1980s, intensive behavioral interventions have become increasingly used to treat children with ASD by assisting them in building skills and reducing maladaptive behaviors. ABA therapy is perhaps the best-known of these therapies. ABA therapy is based on a one-on-one teaching approach that relies on reinforced practice of various skills. ABA therapy is typically provided by certified therapists and a team of behavior technicians, pursuant to a referral from a licensed practitioner such as a neurologist or psychologist. Although state laws are beginning to change, in most states, the therapists and paraprofessional staff who administer ABA therapy, though certified by a national board, are not licensed under state law. While ABA therapy is particularly well-known, many individuals with ASD receive other evidence-
based intensive behavioral interventions. These interventions may be as effective, or even more effective, for some children with ASD, depending on their individual needs. Together, this cohort of intensive behavioral interventions constitutes the standard of care for in treatment for children with ASD.

CMS Issued Guidance on Treatment for ASD in Medicaid Under EPSDT

Since the late 1990s through the 2000s, advocates began to push their states to provide intensive behavioral interventions for ASD in Medicaid. For several years advocates around the county—including NHeLP—have argued that for children with ASD, ABA therapy and other intensive behavioral interventions for ASD must be covered under EPSDT, since they have been shown to be effective treatments at correcting and ameliorating ASD. But many states considered these intensive behavioral interventions to be “habilitative” services aimed at acquiring new skills rather than restoring or preventing deterioration of an existing condition. States are not required to cover habilitative services under EPSDT. As such, many states only provided ABA therapy and other intensive behavioral interventions through a Medicaid waiver home and community-based waiver programs, which may limit the number of children who can get the services and how much of the services they can get. Therefore, not all children with ASD in Medicaid were able to access treatments they need. In the late 2000s, families in Florida, Louisiana, Ohio, and Washington successfully sued their states to obtain coverage of intensive behavioral interventions in Medicaid pursuant to the EPSDT mandate. Moreover, in the months before releasing its July 2014 Guidance, CMS approved requests by Louisiana and Washington to cover ABA therapy under EPSDT.2

NHeLP and other advocates asked CMS to clarify that states must provide evidence-based treatments for children with ASD, including intensive behavioral interventions, under EPSDT. In July 2014, CMS responded to these requests by releasing guidance that explained that states are obligated to cover these services for children under age 21 when they are medically necessary, even if they are not covered for adults in Medicaid. In September 2014, CMS issued an FAQ, further explaining states’ obligation to cover services for children with ASD under EPSDT. The FAQ stated that CMS would be working with states to update and expand the menu of services available to children with ASD. It clarified that CMS would require states that previously only offered intensive behavioral interventions for children with ASD through a Medicaid waiver to transition provision of those services to regular Medicaid program. CMS declined to set a particular deadline by which states must come into compliance with its guidance, but indicated that states should “work expeditiously and should not delay or deny provision of medically necessary services.”

State Activity to Provide Treatment for ASD in Medicaid in the Last Year

Following up on last year’s guidance and FAQ, NHeLP and other advocates quickly began working with states to add intensive behavioral interventions for children with ASD to their state Medicaid programs under EPSDT. Our research suggests that as of September, 2015, 24 states and the District of Columbia are already offering intensive behavioral interventions to children with ASD in their regular Medicaid programs. Following the plans CMS approved last spring for Washington and Louisiana, the agency has approved requests (through state plan amendments) in three additional states to include intensive behavioral interventions for children with ASD in their Medicaid programs.

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1 Home and community-based waiver programs allow states to provide long-term care services in home and community-based settings under the Medicaid Program. Programs can provide a combination of standard medical services and non-medical services. But states can also place limits in these programs that would not be allowed in their regular Medicaid programs. (See CMS 1915(c) Home and Community Based Waivers.)

2 Each state must submit a state Medicaid plan to CMS that sets forth, among other things, the benefits that the state covers in its Medicaid program. When a state changes the benefits offered in its Medicaid program, it generally must submit a proposal, called a “state plan amendment,” to CMS for approval.

October 2015

www.healthlaw.org
Several other states have submitted state plan amendments to CMS proposing to add intensive behavioral interventions to their Medicaid programs (and many of those states have already begun providing services while CMS reviews their proposals). Other states had existing language in their state Medicaid plan that permitted them to offer intensive behavioral interventions without submitting a state plan amendment to CMS. Some states are still in the very early planning stages of drafting a state plan amendment or other policy documents to make intensive behavioral interventions available in their Medicaid programs. Some states have not yet taken any steps to implement the guidance.

Next Steps

While nearly half of states are working to implement CMS’s guidance on services for children with ASD under EPSDT, 25 states have yet to make significant headway. NHeLP is working with advocates in those states to push their states and CMS to ensure that children with ASD gain access to the full scope of services to which they are legally entitled.

Even among the states that have already begun providing intensive behavioral interventions to children with ASD, we are seeing some common themes that can create barriers to care. In many states, advocates report the reimbursement rates for intensive behavioral interventions are very low. As a result, those state Medicaid programs struggle to attract enough trained, quality providers to meet the state’s need. Another common problem is that some states place hard limits on the hours of service Medicaid will provide in a week or a month. These limits, which are illegal under EPSDT, prevent children with the highest need from getting all of the medically necessary care to which they are entitled. (See CMS, EPSDT Coverage Guide at 23.) Another common problem is state refusal to provide services to children during the school day. Such limitations violate EPSDT and can prevent children who experience the most severe symptoms of their ASD at school from receiving adequate treatment. See 42 U.S.C. § 1396b(c). NHeLP is working with advocates around the country to address these and other barriers to care under EPSDT. We encourage advocates to work with CMS and their states to ensure that intensive behavioral interventions for children with ASD are available through Medicaid whenever they are needed.
EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents

Early and Periodic Screening, Diagnostic and Treatment (EPSDT)

JUNE 2014

Available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html
V. PERMISSIBLE LIMITATIONS ON COVERAGE OF EPSDT SERVICES

A. Individual Medical Necessity

Services that fit within the scope of coverage under EPSDT must be provided to a child only if necessary to correct or ameliorate the individual child’s physical or mental condition, i.e., only if “medically necessary.” The determination of whether a service is medically necessary for an individual child must be made on a case-by-case basis, taking into account the particular needs of the child. The state (or the managed care entity as delegated by the state) should consider the child’s long-term needs, not just what is required to address the immediate situation. The state should also consider all aspects of a child’s needs, including nutritional, social development, and mental health and substance use disorders. States are permitted (but not required) to set parameters that apply to the determination of medical necessity in individual cases, but those parameters may not contradict or be more restrictive than the federal statutory requirement. As discussed above, services such as physical and occupational therapy are covered when they have an ameliorative, maintenance purpose.

**Determination of whether a service is medically necessary must be made on a case-by-case basis, taking into account a particular child’s needs.**

Because medical necessity decisions are individualized, flat limits or hard limits based on a monetary cap or budgetary constraints are not consistent with EPSDT requirements. 42 States may adopt a definition of medical necessity that places tentative limits on services pending an individualized determination by the state, or that limits a treating provider’s discretion, as a utilization control, but additional services must be provided if determined to be medically necessary for

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42 HCFA, Regional Transmittal Notice (Region IV) (Sept. 18, 1990); Memorandum from Rozann Abato, Acting Director, HCFA, to Associate Regional Administrator, Atlanta (Sept. 5, 1990); Memorandum from Christine Nye, HCFA Medicaid Director, to Regional Administrator Region VIII (FME-42) (1991).
an individual child.\textsuperscript{43} For example, while a state may place in its State Plan a limit of a certain number of physical therapy visits per year for individuals age 21 and older, such a "hard" limit could not be applied to children. A state could impose a "soft" limit of a certain number of physical therapy visits annually for children, but if it were to be determined in an individual child's case, upon review, that additional physical therapy services were medically necessary to correct or ameliorate a diagnosed condition, those services would have to be covered.

While the treating health care provider has a responsibility for determining or recommending that a particular covered service is needed to correct or ameliorate the child's condition,\textsuperscript{44} both the state and a child's treating provider play a role in determining whether a service is medically necessary. If there is a disagreement between the treating provider and the state's expert as to whether a service is medically necessary for a particular child, the state is responsible for making a decision, for the individual child, based on the evidence. That decision may be appealed by the child (or the child's family) under the state's Medicaid fair hearing procedures, as described in Section VIII below.

\section*{B. Prior Authorization}

States may impose utilization controls to safeguard against unnecessary use of care and services. For example, a state may establish tentative limits on the amount of a treatment service a child can receive and require prior authorization for coverage of medically necessary services above those limits.\textsuperscript{45} Prior authorization must be conducted on a case-by-case basis, evaluating each child's needs individually. Importantly, prior authorization procedures may not delay delivery of needed treatment services and must be consistent with the "preventive thrust" of EPSDT.\textsuperscript{46} As such, prior authorization may not be required for any EPSDT screening services. In addition, medical management techniques used for mental health and substance use disorders should comply with the Mental Health Parity and Addiction Equity Act.

\section*{C. Experimental Treatments}

EPSDT does not require coverage of treatments, services, or items that are experimental or investigational. Such services and items may, however, be covered at the state's discretion if it is determined that the treatment or item would be effective to address the child's condition.\textsuperscript{47} Neither the Federal Medicaid statute nor the regulations define what constitutes an experimental

\textsuperscript{43} 42 C.F.R. §§ 440.230(c), (d); HCFA Dear State Medicaid Director (May 26, 1993).
\textsuperscript{44} Sections 1905(a) and (r) of the Social Security Act.
\textsuperscript{45} Id.
\textsuperscript{47} CMS, State Medicaid Manual §§ 4385.C.1, 5122.F.
Civil Rights

Section 1557 of the Patient Protection and Affordable Care Act

Section 1557 is the civil rights provision of the Affordable Care Act. Section 1557 prohibits discrimination on the ground of race, color, national origin, sex, age, or disability under “any health program or activity, any part of which is receiving Federal financial assistance ... or under any program or activity that is administered by an Executive agency or any entity established under [Title I of ACA]....” Section 1557 is the first Federal civil rights law to prohibit sex discrimination in health care. To ensure equal access to health care, Section 1557 also applies civil rights protections to the newly created Health Insurance Marketplaces established under the Affordable Care Act.

Section 1557 is consistent with and promotes several of the Administration’s key initiatives that advance prevention and wellness, reduce health disparities, and improve access to health care services. The Office for Civil Rights in HHS is responsible for enforcing Section 1557 with respect to covered programs. The law was effective upon enactment and OCR has been accepting and investigating complaints under this authority. If you believe you have been discriminated against on one of the bases protected by Section 1557, you may file a complaint with OCR. OCR also addresses Section 1557 in conducting outreach and providing technical assistance to covered entities and consumers.

ACA Enforcement: Sex Discrimination Cases

OCR Issues Proposed Rule on Nondiscrimination under Section 1557 of the Affordable Care Act

Note that the comment period ended at midnight on November 9, 2015. The NPRM is available for review at: http://www.regulations.gov/#/docketDetail?D=HHS-OCR-2015-0006

- Click here for a Summary
- Español, 中文, Tiếng Việt, 한국어, Tagalog, Русский, العربية, Kreyòl ayisyen, Français, Português, Polsk, i日本語, Italiano, Deutsch, فارسی

- Click here for the Questions and Answers about the NPRM

- Español, 中文, Tiếng Việt, 한국어, Tagalog, Русский, العربية, Kreyòl ayisyen, Français, Português, Polsk, i日本語, Italiano, Deutsch, فارسی

- Click here for the Press Release

- For documents in alternative formats, please call (800) 368-1019 or (800) 537-7697 (TDD)

Content created by Office for Civil Rights (OCR)

http://www.hhs.gov/civil-rights/for-individuals/section-1557/index.html

4/10/2016
Time Limits for Filing a Charge of Discrimination

Before you can sue your employer for discrimination, you must first file a charge of discrimination with the EEOC or a similar state agency.

Before an employee may sue for discrimination, harassment, or retaliation (topics/discrimination-and-harassment) under federal law, the employee must file a charge of discrimination with the Equal Employment Opportunity Commission (EEOC) and get a right to sue letter. This is a necessary prerequisite to filing a lawsuit: If an employee files a lawsuit without first filing an administrative charge, the lawsuit will be dismissed.

Which Laws Are Covered

An employee is required to file a charge of discrimination with the EEOC before filing a lawsuit against an employer for violating Title VII (the federal law that prohibits discrimination on the basis of race, color, national origin, religion, and sex), the Americans with Disabilities Act (american-disabilities-act.cfm), the Age Discrimination In Employment Act, or the Genetic Information Nondiscrimination Act. An employee alleging harassment or retaliation under any of these laws must also first file a charge. However, an employee does not have to file a charge before bringing a lawsuit for violation of the Equal Pay Act, which requires employees to pay men and women equally for equal work.

Most states have their own laws that prohibit certain types of discrimination. Some states also require employees to file a charge of discrimination before filing a lawsuit for violation of state law; others don't.

Learn more about Your Rights in a Discrimination Case (topics/asserting-your-rights).

Time Limits for Filing a Charge

The statute of limitations for filing a charge of discrimination depends on state and local law. Generally, an employee has 180 days from the date the alleged discrimination took place to file a charge. If a state or local agency enforces a law prohibiting the same type of discrimination, the time limit is extended to 300 days. For age discrimination cases, the rule is different: The deadline is extended to 300 days only if a state agency (not a local agency) enforces a law prohibiting age discrimination.
Work-Sharing Agreements

In many states, the EEOC has entered into a work-sharing agreement with the state fair employment practices agency. If you file a charge of discrimination with either the EEOC or the state agency in one of these states, it will automatically be filed with the other agency, too. If your state doesn't have a work-sharing agreement, and you want to preserve your rights under both federal and state law, you may file a charge with both agencies yourself.

Filing a Charge

Currently, you may file a charge of discrimination with the EEOC in person or by mail. To file by mail, you must include the following information:

- your name, address, and phone number
- the name, address, and phone number of the employer
- how many employees the employer has
- a short description of the discriminatory incident(s), including when it took place, and
- the basis for the discrimination (that is, whether the employer discriminated against you based on race, religion, or sex, for example).

You can find detailed information on the EEOC's charge-filing procedures at the EEOC website (http://www.eeoc.gov). To find out how to file a charge of discrimination under state law, contact your state's fair employment practices agency.

Getting Legal Help

If you believe you have been discriminated against, you may want to contact an experienced employment lawyer right away. A lawyer can help you figure out how best to protect your rights going forward, including whether and when to file a charge of discrimination and what to include in it. Once you file a charge, a lawyer can help you negotiate with your employer, participate in the agency's investigation (if there is one), and file a lawsuit.

http://www.employmentlawfirms.com/statutes-of-limitations.cfm
File a Charge

NAVIGATE

Discrimination Home (/discrimination/)
Practices (/discrimination/discriminatory-practices.php)
Race/Color (/discrimination/race.php)
Sex-Based (/discrimination/sex-discrimination.php)
Sexual Harassment (/discrimination/sexual-harassment.php)
Sexual Orientation (/discrimination/sexual-orientation.php)
Pregnancy (/discrimination/pregnancy.php)
Disability (/discrimination/disability.php)
Age (/discrimination/age.php)

National Origin (/discrimination/national-origin.php)

Religion (/discrimination/religion.php)

File a Charge (/discrimination/file-a-charge.php)

Charge Processing Procedures (/discrimination/procedures.php)

What An Employer Should Know (/discrimination/what-an-employer-should-know.php)

Mediation at DDOL (/discrimination/mediation.php)

Facts About Mediation (/discrimination/mediation-facts.php)

Discrimination Intake Form (/discrimination/discrimination-questionnaires.php)


NOTE: Federal employees or applicants for Federal employment should contact the EEOC for information on procedures to make a complaint of discrimination.

Who Can File a Charge of Discrimination?

- Any individual who believes that his or her employment rights have been violated under the Delaware Discrimination in Employment Act (http://delcode.delaware.gov/title19/c007/sc02/index.shtml) or the Handicapped Persons Employment Protections Act (http://delcode.delaware.gov/title19/c007/sc03/index.shtml) may file a charge of discrimination with DDOL.

How is a Charge of Discrimination filed?

- A charge may be filed in person at the DDOL office in Dover or Wilmington.
- You may start the process by downloading and completing Discrimination Intake Form (discrimination-questionnaires.php). Submit the completed questionnaire to our offices. We will contact you to set up an appointment to finalize the filing process.
- Individuals who need an accommodation in order to file a charge (e.g., sign language interpreter, print materials in an accessible format) should inform the DDOL office in advance so appropriate arrangements can be made.

What Information Must Be Provided to File a Charge?

- The complaining party's name, address, and telephone number;
• The name, address, and telephone number of the respondent employer, employment agency, or union that is alleged to have discriminated, and number of employees (or union members), if known;
• A short description of the alleged violation (the event that caused the complaining party to believe that his or her rights were violated); and
• The date(s) of the alleged violation(s).
• The **Discrimination Intake Form** ([discrimination-questionnaires.php](http://www.addthis.com/bookmark.php?v=250&pub=stateofdelaware)) will help you gather the information we will need for your specific situation.

**What Are the Time Limits for Filing a Charge of Discrimination?**

All laws enforced by DDOL require filing a charge with DDOL before a private lawsuit may be filed in court. There are strict time limits within which charges must be filed:

• A charge must be filed with DDOL within 120 days from the date of the alleged violation, in order to protect the charging party's rights to file an action in state court.
• The filing deadline is to 300 days under federal law. A charge filed between 121 and 300 days will be forwarded to the EEOC for processing.
• To protect legal rights, it is always best to contact DDOL promptly when discrimination is suspected.

**What Agency Handles a Charge that is also Covered by Federal Law?**

Through the use of "work sharing agreements," EEOC and the DDOL avoid duplication of effort while at the same time ensuring that a charging party’s rights are protected under both federal and state law.

• If a charge is filed with the DDOL and is also covered by federal law, the DDOL "dual files" the charge with EEOC to protect federal rights. The charge usually will be retained by the DDOL for handling.
• If a charge is filed with EEOC and also is covered by state or local law, EEOC "dual files" the charge with the state or local FEPA, but ordinarily retains the charge for handling.
A push to end shackling of children in Delaware courts

Children and teens appear every day in Delaware courtrooms with ankles locked together by metal leg irons. Their crimes range from drug possession and theft to gun charges and rape. All are in state custody because they cannot afford to post bail. All are presumed innocent until proven guilty.

"They are shackled and brought into court like a slave more or less," said state Rep. James Johnson, D-New Castle. "That is something that will stick with you the rest of your life."

Defense attorneys and child advocates say this daily scene in Family Court is grisly — youth are restrained and left traumatized by a criminal justice system that is supposed to rehabilitate, not punish, them. That is why there is an effort to end the shackling of youth during proceedings at the the state’s three courthouses.

Adult defendants in Delaware are not usually shackled during trials so as not to influence juries. Typically, adult defendants wear leg irons only during other court proceedings.

For juveniles, handcuffs and belly chains are removed once they get to the courtroom, but leg irons remain during all proceedings. Nearly half of all states have ended this practice in the United States.

Johnson introduced a bill in the House of Representatives in June to limit the use of shackles except in rare circumstances where the court can show that restraints are necessary to prevent flight or physical harm to the child or others. The bill is on hold in the House Judiciary Committee and could get support if the Department of Services for Children, Youth and Their Families doesn’t change its policy on shackling juveniles on its own.

WHEREAS, juvenile delinquency proceedings in Delaware’s Family Court are rehabilitative in nature and in the interests of order and justice against the child; and

WHEREAS, Delaware law prohibits a child’s release to the delinquent’s home being granted in cases where a reasonable possibility of the child’s return to that home is not established;

WHEREAS, the liberty of children is a liberty of the child’s family;

WHEREAS, the mandatory or involuntary shackling of juveniles in custody during their court appearances is contrary to the rehabilitative purpose of the juvenile justice system; and

WHEREAS, the United States Supreme Court has held the mandatory shackling of adult defendants unconstitutional because visible shackling undermines the pretrial presumption of innocence and can interfere with an accused’s ability to communicate with their attorney; and

WHEREAS, the American Bar Association has adopted a resolution urging all federal, state, local, tribal and tribal governments to adopt a presumption against the use of restraints on juveniles in court and permitting the use of restraints only when necessary to prevent flight or injury to the juvenile or others; and

WHEREAS, the American Academy of Child & Adolescent Psychiatry has issued a policy statement opposing mandatory or involuntary shackling of juveniles as “detrimental, stigmatizing and stigmatising” of juveniles and a practice that aids in the trauma many juveniles involved in court already experience; and

WHEREAS, other child advocacy organizations – including the Child Welfare League of America, the American Orthopsychiatric Association, the National Center for Victims Health and Juvenile Justice, the National Association for the Advancement of Colored People, the National Council of Churches and the National Juvenile Defender Council – all oppose the involuntary use of physical restraints on youth appearing in court; and

WHEREAS, the General Assembly believes the use of physical restraints on youth appearing in court should occur only in those rare cases where no less restrictive alternatives will prevent flight or physical harm to the child or other court personnel;

NOW, THEREFORE:

Page 1 of 2

Delaware courts: Some push to end shackling of children

The department’s division that monitors youth detention and transport to court is looking forward to young people attending court tree or snacks, a spokeswoman said, but is concerned about the layout of the Family Court facilities in Dover and Georgetown. The 3-decade-old courts are in desperate need of upgrades and pose security concerns, court officials have said.

In November, Delaware Supreme Court Chief Justice Leo E. Strine Jr. stressed to lawmakers the need for funds to upgrade these buildings.

One judge in Dover was spat on by an inmate when they were forced to share the same elevator in the back of the courthouse, according to an attorney. And because the facilities are small, those seeking protective orders bump into people they are accusing and lawyers have little space to discuss cases with their clients.

"We will need to work with our system partners – Family Court, the Attorney General’s Office and the Public Defender’s Office – to ensure that any changes that are implemented can be done in a way that can provide for the safety of the youth and others in the courthouse provided the challenges of the physical plant in some of the court facilities," department spokeswoman Dawn Thompson said in a statement.

Delaware Chief Public Defender Brendan O’Neill said the matter is pressing and can’t wait for those changes.

"The practice of routinely shackling kids coming into court without an affirmative finding that they pose a genuine security risk is just flat out wrong," he said. "We are trying to change it."

**Feeling like a ‘caged animal’**

In January 2014, the National Juvenile Defender Center, a nonprofit in Washington, D.C., launched a nationwide campaign to end indiscriminate juvenile shackling. The campaign comes amid a flurry of criminal justice reform efforts, including pushes to end the money bail system [story/news/crime/2015/11/07/bail-leave-courts-ball/746192680] and a proposal to scale back mandatory minimum sentences [story/news/crime/2015/12/28/inmates-serving-life-prison-hope-end-three-strikes-law/767925260].

"People are realizing that the things we have done in the past have not worked and should be changed," Johnson said. "This is one of the changes that should be made."

Twenty-three states have banned the practice of juvenile shackling either by legislation or court order. About half of those have done so since 2014.

Most recently, in September, the Maryland Court of Appeals and the state Judicial Council adopted an anti-shackling policy that leaves the decision to shackles a youth up to a judge if there are safety concerns.

Maryland Public Defender Paul B. DeWolfe, a strong supporter of the change, wrote in an editorial in the Baltimore Sun last year that during the media storm surrounding the death of Freddie Gray, one instance of juvenile shackling stood out to him. A teen was arrested by Baltimore police during protests and told an NBC reporter that being shackled felt like a "caged animal" (http://www.baltimorepost.com/news/opinion/oped/ba-md-shackling-juveniles-20150519-story.html)

"It’s tragic," DeWolfe told The News Journal. "It’s tragic to see a 12- or 13-year-old coming into a courtroom ... in chains. It’s completely unnecessary and goes against the whole principle of juvenile court."

Delaware courts: Some push to end shackling of children

Six in 10 Delaware inmates are black

DELAWAREONLINE

Will death penalty ruling affect Delaware?

DeWolfe praised the end of the practice in Maryland, but said there are still some jurisdictions not complying with the new policy. In particular, Baltimore has resisted the change and continued to keep leg irons or handcuffs on children during hearings, he said.

"We are litigating those cases and trying to get that before the Court of Appeals," he said. "But, by and large across the state, once the proclamation was put into effect, the practice stopped. It's been a great success and long overdue."

Christina Gilbert, a staff attorney and policy counsel at the National Juvenile Defender Center, said this shows the importance of ensuring the change is mandatory statewide.

"A number of states, I anticipate, in addition to Delaware, will shift in the next year or so," she said.

What does Delaware do?

Juveniles who are detained in Delaware are transported by the Division of Youth Rehabilitative Services to the state’s three courthouses in Kent, Sussex and New Castle counties.

When they arrive, handcuffs and belly chains are removed, but leg irons remain during court proceedings. On a case-by-case basis, judges can consider if an individual poses a safety risk and should have the additional restraints left on.

Even with the restraints on, youth can still pose a risk, some say. For example, a 17-year-old defendant kicked out the window in a van that was taking him in shackles from a family court proceeding in September.

Wilmington police searching for a 17-year-old who escaped from a juvenile correction van in September. He was caught about a month later. (Photo: JOHN J. JANKOWSKI JR., SPECIAL TO THE NEWS JOURNAL)

He jumped out of the moving vehicle in Wilmington and was on the run from authorities for about a month.

Advocates say these types of scenarios are rare — and need to be weighed against the more widespread harm that shackles can inflict on children.

The developing brain

Attempts by The News Journal to speak with youth who have been detained and their families were unsuccessful.

Karen DeRasmo, executive director of Prevent Child Abuse Delaware, said the experience of being shackled can impact a child's brain at a time when it is still developing.

"What we always have to imagine and appreciate is that kids' brains are in the process of developing," she said. "They tend to think much more concretely about things. They don't have some of the higher level of thought processes that adults have."

For that reason, shackling could be traumatizing to a young person, especially because those who are entering the juvenile justice system are probably already experiencing a higher level of toxic stress in life, she said.

"It could indeed cause them more trauma because they don't have the same facilities to deal with that situation," she said. "It could actually affect the way their brain is developing and how they are going to view the world going forward."

Gilbert said eliminating juvenile shackling can also change the courtroom environment from one of an authoritative, penal system to one of openness and fairness.

"We know that the idea of procedural justice is so important to youth," she said. "The juvenile court is designed to be different from the adult court system. It is supposed to be rehabilitative, not punishing."

Shackling also more heavily impacts poor black and Hispanic youth who enter the system and cannot afford to pay bail, O'Neill and DeRasmo said.

In 2014, 4,303 juveniles arrested in Delaware and 1,038 admissions into juvenile detention facilities. Of those detained, 71.8 percent were African-American (https://www.google.com/search?q=delaware+juvenile+statistics+2014&ie=utf-8&oe=utf-8) — making it seven times more likely that African-American youth will be placed in a state detention center than white youth.

"It seems like one more way we are doing harm when we don't have to," DeRasmo said.

Although House Bill 211 is on hold, Johnson said that if an agreement with the children's department does not eliminate juvenile shackling soon, the bill could be put to the forefront in the legislative session.

"I think now is the time," Johnson said. "We want to move forward with it."

Contact Jessica Masulli Reyes at (302) 324-2777, jmreyes@delawareonline.com or Twitter @JessicaMasulli.

Read or Share this story: http://delonline.us/1VgP7Vg
Shackling children is not fair or just in my court

DELAWARE VOICE
JUDGE DARLENE BYRNE

Juvenile court is where kids who have broken the law come to take responsibility. As a judge and a parent, I know that if there are better ways to demonstrate responsibility than shackling them, I should give lectures on the topic. That is one reason why I put a stop to the automatic shackling of children in my courtroom. I have a responsibility to see that everyone is treated fairly and that the court works effectively to rehabilitate children. There is nothing fair or rehabilitative about wrapping a child in chains.

My courtroom is in Texas, where like Delaware and 25 other states there are no restrictions on shackling in the juvenile court. Case law has long established that adult defendants cannot usually be shackled. That protection has never been extended to kids. So in most of the country, kids are routinely bound in handcuffs, leg irons and belly chains.

This is changing. Delaware's legislature will soon consider a proposal to put reasonable limits on juvenile shackling. In the past two years, 10 states and the District of Columbia have reformed their practices. National organizations from the Child Welfare League of America to the American Bar Association to my organization, the National Council of Juvenile and Family Court Judges, are calling for such limits. This is an idea whose time, thank goodness, has finally come.

I decided not to wait for the law to change before I reformed practice in my own courtroom. The outcomes have been outstanding. We hear about 3,000 juvenile cases in my district. In only two cases did I deem shackles necessary because those youth posed a significant risk. In more than a year since I and all my colleagues have stopped automatic shackling, there have been no escapes and no violence.

Far more compelling is what did happen: More engaged kids and families, more meaningful conversations, more success. Certainly juvenile courts are charged with holding kids accountable. We never take law breaking lightly. Our primary mission, however, is to rehabilitate. As a juvenile judge, I work in partnership with many professionals to find and address those factors that are leading to problem behavior. It is often an untreated mental illness, unresolved trauma, family dysfunction or learning difficulties.

It helps if the child is willing to really talk to me — not merely mumble one-syllable answers as he looks down at his shackled feet. It helps if the parents see me as a caring partner in their child's success. If I allow their child to be paraded about in chains, I have not earned anyone's trust.

The juvenile court was established to rehabilitate, and shackling makes that less likely. While juvenile shackling reform has been led by juvenile defenders in some states, prosecutors are supportive as well. The Association of Prosecuting Attorneys supports juvenile shackling reform precisely because the change will make more kids successful and less likely to come back to court again. Research shows that youth who experience procedural fairness gain respect for the law and are more likely to cooperate with the court.

Even more fundamentally, shackling reform is the right thing to do for our children. Mental health experts across the country warn that shackling is such a negative experience that it can do permanent harm to children, particularly those who have survived trauma, as the vast majority of kids in the juvenile justice system have. I want the children who come into my courtroom to feel remorse for what they have done. That is justice. But I do not want to humiliate or traumatize them in any way. That is not justice. It is something else entirely.

Darlene Byrne is president of the National Council for Juvenile and Family Court Judges.
A bill that would stop the shackling of juvenile defendants in court and a bill that would scale back the state's three-strikes laws breezed through their first steps in the General Assembly Wednesday.

House Bill 211, sponsored by Rep. J.J. Johnson, D-New Castle, would require that courts not shackle juvenile defendants unless there is a particular need to do so. Currently, Johnson says courts are shackling young defendants by default.

"This legislation, to me, is bringing our justice system into the 21st century," Johnson said.

A News Journal article in January exposed the practice of shackling children and teens who appear in Delaware courthouses.

Defense attorneys, lawmakers and child advocates argued at the time that the daily scene in Family Court was grisly with youth being restrained by heavy metal leg irons.

The bill's supporters, including the ACLU, public defender's office and state Supreme Court Chief Justice Leo Strine Jr., say shackles are psychologically damaging to young defendants and naturally make them seem guilty, hurting the presumption of their innocence around which the justice system is built.

Johnson also argues shackles are a troubling symbol "quite similar to a noose." He showed legislators some of the shackles at a Wednesday meeting in the House Judiciary Committee, the chains clinking as he moved.

"This is something we should have moved away from years ago," Johnson said.


The House Judiciary Committee unanimously voted Wednesday to send the bill to the full House. Should the House approve the bill, it would also have to pass the Senate before heading to Gov. Jack Markell's desk.

Later, the Senate Judiciary Committee released a bill by Sen. Karen Peterson, D-Stanton, that would curtail the habitual offender or "three-strikes" laws (http://legis.delaware.gov/legislature/ssf/main?OpenFrameset&Frame=right&src=legislature.nsf/7F4F68DC9595E8E0D1852569C10056E9D4/39AA2F3C3C34CF5A815257F09E005A56C7) that place mandatory harsh penalties on people convicted of a felony offense after two previous crimes. The bill would eliminate mandatory life sentences and remove some crimes from the list of offenses that trigger mandatory sentences.

Supporters of the bill, from Attorney General Matt Denn to the ACLU, say the current law ties judges' hands and leads to some people getting disproportionately harsh penalties.

The bill has to pass both the full Senate and the House before heading to Markell for signature.

Contact Matthew Albright at malbright@delawareonline.com, (302) 324-2428, or on Twitter @TNJ_malbright.
Read or Share this story: http://delonline.us/1poJN89

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**148TH GENERAL ASSEMBLY**

**FISCAL NOTE**

BILL:         HOUSE BILL NO. 211

SPONSOR:     Representative J. Johnson

DESCRIPTION: AN ACT TO AMEND TITLE 10 OF THE DELAWARE CODE RELATING TO JUVENILE DELINQUENCY PROCEEDINGS AND THE USE OF RESTRAINTS ON A CHILD.

**ASSUMPTIONS:**

1. This legislation is effective upon enactment.

2. This Act limits the use of shackles and other physical restraints on children appearing in juvenile delinquency proceedings except in situations where the court determines that the use of restraints is necessary and there are no less restrictive alternatives that will prevent flight or physical harm to the child or other courtroom participants.

3. The Department of Children, Youth and Their Families, Division of Youth Rehabilitative Services (YRS) is responsible for the transportation of juveniles from both the New Castle County Detention Center (NCCDC) and the Stevenson House facilities to Family Court that would be impacted by this Act.

4. There are currently 9.0 full-time and 1.0 casual/seasonal positions dedicated as Youth Rehabilitative Counselors, two of which are Youth Rehabilitative Counselor Supervisors. The current population at NCCDC is approximately 50 juveniles and 45 juveniles at Stevenson House. This unit is responsible for transportation to and from Family Court, Superior Court, and any medical related transports.

5. Based on current resources, YRS has indicated for the safety of all involved, 4.0 additional full-time Youth Rehabilitative Counselors are required to cover statewide Family Court trips. This will enable two YRS staff members to be present with each youth in a court room. In order to meet the requirements of Preventing Prison Rape Act (PREA), at least one position will be female.

6. The estimated State agency costs for the 4.0 additional full-time Youth Rehabilitative Counselors is $232,996.24 (estimate includes salary and other employment costs (OEC's)).

**Cost:**

<table>
<thead>
<tr>
<th>Fiscal Year</th>
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<td>2019</td>
<td>$232,996.24</td>
</tr>
</tbody>
</table>

Office of Controller General
March 15, 2016
KARN:KARN
4531480007

(Amounts are shown in whole dollars)
Disability Statistics (/)
Online Resource for U.S. Disability Statistics

Find U.S. disability statistics in 3 easy steps

Select a Statistic  Adjust Search Filters  Review Results

http://www.disabilitystatistics.org/reports/acs.cfm?statistic=2
Disability Statistics

Individual Statistics

American Community Survey
- Prevalence
  (.reports.acs.cfm?statistic=1)
- Employment Rate
  (.reports.acs.cfm?statistic=3)
- Full-Time / Full-Year Employment
  (.reports.acs.cfm?statistic=4)
- Annual Earnings
  (.reports.acs.cfm?statistic=5)
- Annual Household Income
  (.reports.acs.cfm?statistic=6)
- Poverty
  (.reports.acs.cfm?statistic=7)
- Supplemental Security Income (SSI)
  (.reports.acs.cfm?statistic=8)
- Educational Attainment
  (.reports.acs.cfm?statistic=9)

Search Form

Source: American Community Survey (ACS)
(.g_id=270&view=true)

Statistic: Employment Rate
(.g_id=255&view=true)

Gender: Male or Female
(.g_id=236&view=true)

Disability Status: with
(.g_id=286&view=true)

Disability Type: Any Disability
(.g_id=234&view=true)

Age: Ages 21-64
(.g_id=275&view=true)

Race: all races
(.g_id=254&view=true)

Education: all education levels
(.g_id=275&view=true)

Hispanic: regardless of ethnicity
(.g_id=254&view=true)

Value: Percentage

Year: 2013

Search

Table

Employment Rate:
The percentage of non-institutionalized, male or female, with a
disability, ages 21-64, all races, regardless of ethnicity, with all
education levels in the United States who were employed in
2013.

<table>
<thead>
<tr>
<th>Location</th>
<th>Estimate (%)</th>
<th>90% MOE</th>
<th>Base Population</th>
<th>Sample Size</th>
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</thead>
<tbody>
<tr>
<td>United States</td>
<td>34.5</td>
<td>± 0.28</td>
<td>19,618,200</td>
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<tr>
<td>Alabama</td>
<td>27.2</td>
<td>± 1.59</td>
<td>409,700</td>
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<td>Alaska</td>
<td>50.8</td>
<td>± 5.44</td>
<td>44,000</td>
<td>418</td>
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<td>Arizona</td>
<td>33.5</td>
<td>± 1.77</td>
<td>372,300</td>
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<td>28.0</td>
<td>± 2.02</td>
<td>260,300</td>
<td>2,777</td>
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<td>32.8</td>
<td>± 0.78</td>
<td>1,917,800</td>
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<td>Colorado</td>
<td>42.7</td>
<td>± 2.09</td>
<td>293,300</td>
<td>2,915</td>
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<td>Connecticut</td>
<td>41.7</td>
<td>± 2.71</td>
<td>173,600</td>
<td>1,820</td>
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<td>Delaware</td>
<td>36.1</td>
<td>± 4.51</td>
<td>59,500</td>
<td>572</td>
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<tr>
<td>District of Columbia</td>
<td>32.8</td>
<td>± 5.57</td>
<td>37,300</td>
<td>390</td>
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<tr>
<td>Florida</td>
<td>30.8</td>
<td>± 0.98</td>
<td>1,159,900</td>
<td>11,763</td>
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<tr>
<td>Georgia</td>
<td>32.4</td>
<td>± 1.33</td>
<td>661,600</td>
<td>6,600</td>
</tr>
<tr>
<td>Hawaii</td>
<td>42.2</td>
<td>± 4.49</td>
<td>63,500</td>
<td>639</td>
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<tr>
<td>Idaho</td>
<td>37.6</td>
<td>± 3.49</td>
<td>101,100</td>
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<td>Illinois</td>
<td>37.0</td>
<td>± 1.33</td>
<td>691,000</td>
<td>7,194</td>
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<td>Indiana</td>
<td>35.1</td>
<td>± 1.59</td>
<td>474,300</td>
<td>4,947</td>
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<td>Iowa</td>
<td>43.6</td>
<td>± 2.30</td>
<td>179,300</td>
<td>1,786</td>
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<td>Kansas</td>
<td>42.3</td>
<td>± 2.73</td>
<td>171,700</td>
<td>1,813</td>
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<tr>
<td>Kentucky</td>
<td>27.6</td>
<td>± 1.61</td>
<td>404,100</td>
<td>4,056</td>
</tr>
<tr>
<td>Louisiana</td>
<td>31.9</td>
<td>± 1.79</td>
<td>354,500</td>
<td>3,610</td>
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<tr>
<td>Maine</td>
<td>32.1</td>
<td>± 2.92</td>
<td>115,500</td>
<td>1,091</td>
</tr>
</tbody>
</table>

http://www.disabilitystatistics.org/reports/acs.cfm?statistic=2

3/28/2016
## Disability Statistics

### Current Population Survey
- Prevalence (cps.cfm?statistic=prevalence)
- Labor Market Activity (cps.cfm?statistic=activity)
- Employment (cps.cfm?statistic=employment)
- Household Income (cps.cfm?statistic=houseinc)
- Poverty (cps.cfm?statistic=poverty)

| State          | Prevalence Rate | Population | Persons
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Maryland</td>
<td>41.2 ± 2.02</td>
<td>312,700</td>
<td>3,122</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>34.6 ± 1.78</td>
<td>376,200</td>
<td>3,799</td>
</tr>
<tr>
<td>Michigan</td>
<td>30.4 ± 1.13</td>
<td>748,800</td>
<td>7,738</td>
</tr>
<tr>
<td>Minnesota</td>
<td>44.0 ± 1.83</td>
<td>282,900</td>
<td>2,983</td>
</tr>
<tr>
<td>Mississippi</td>
<td>26.7 ± 1.94</td>
<td>272,400</td>
<td>2,798</td>
</tr>
<tr>
<td>Missouri</td>
<td>32.4 ± 1.61</td>
<td>442,900</td>
<td>4,662</td>
</tr>
<tr>
<td>Montana</td>
<td>38.0 ± 3.57</td>
<td>69,700</td>
<td>658</td>
</tr>
<tr>
<td>Nebraska</td>
<td>45.9 ± 3.22</td>
<td>92,400</td>
<td>991</td>
</tr>
<tr>
<td>Nevada</td>
<td>41.1 ± 2.59</td>
<td>189,000</td>
<td>1,785</td>
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<tr>
<td>New Hampshire</td>
<td>40.5 ± 3.94</td>
<td>81,700</td>
<td>787</td>
</tr>
<tr>
<td>New Jersey</td>
<td>37.5 ± 1.70</td>
<td>423,800</td>
<td>4,302</td>
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<tr>
<td>New Mexico</td>
<td>35.6 ± 2.75</td>
<td>159,200</td>
<td>1,440</td>
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<tr>
<td>New York</td>
<td>32.6 ± 1.05</td>
<td>1,044,300</td>
<td>11,274</td>
</tr>
<tr>
<td>North Carolina</td>
<td>31.4 ± 1.29</td>
<td>680,800</td>
<td>7,015</td>
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<tr>
<td>North Dakota</td>
<td>56.0 ± 5.28</td>
<td>34,100</td>
<td>351</td>
</tr>
<tr>
<td>Ohio</td>
<td>33.9 ± 1.21</td>
<td>808,400</td>
<td>8,391</td>
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<tr>
<td>Oklahoma</td>
<td>37.0 ± 1.72</td>
<td>303,800</td>
<td>3,118</td>
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<tr>
<td>Oregon</td>
<td>35.3 ± 2.00</td>
<td>300,400</td>
<td>2,772</td>
</tr>
<tr>
<td>Pennsylvania</td>
<td>33.6 ± 1.20</td>
<td>820,100</td>
<td>8,185</td>
</tr>
<tr>
<td>Rhode Island</td>
<td>34.6 ± 4.33</td>
<td>63,400</td>
<td>650</td>
</tr>
<tr>
<td>South Carolina</td>
<td>31.5 ± 1.79</td>
<td>352,200</td>
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<td>South Dakota</td>
<td>49.1 ± 4.20</td>
<td>54,600</td>
<td>516</td>
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<td>Tennessee</td>
<td>30.2 ± 1.44</td>
<td>537,500</td>
<td>5,526</td>
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<td>Texas</td>
<td>38.8 ± 0.90</td>
<td>1,553,500</td>
<td>15,661</td>
</tr>
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<td>Utah</td>
<td>42.2 ± 3.03</td>
<td>139,700</td>
<td>1,417</td>
</tr>
<tr>
<td>Vermont</td>
<td>34.6 ± 4.20</td>
<td>41,500</td>
<td>400</td>
</tr>
<tr>
<td>Virginia</td>
<td>36.8 ± 1.64</td>
<td>452,600</td>
<td>4,660</td>
</tr>
<tr>
<td>Washington</td>
<td>37.5 ± 1.64</td>
<td>458,300</td>
<td>4,612</td>
</tr>
<tr>
<td>West Virginia</td>
<td>25.3 ± 2.05</td>
<td>202,900</td>
<td>1,951</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>41.7 ± 1.64</td>
<td>347,500</td>
<td>3,430</td>
</tr>
</tbody>
</table>
Written Description

Description of Statistics

In the year 2013, an estimated 34.5 percent (plus or minus 0.28 percentage points) of non-institutionalized, male or female, with a disability, ages 21-64, all races, regardless of ethnicity, with all education levels in the United States were employed.

In other words, 6,775,300 out of 19,618,200 non-institutionalized, male or female, with a disability, ages 21-64, all races, regardless of ethnicity, with all education levels in the United States were employed.

The estimates above are based on a sample of 199,997 persons who participated in the 2013 American Community Survey (ACS).

These estimates may differ slightly from the Census Bureau summary tables. See Frequently Asked Questions (faq.cfm?n=7#Q4) for more information.

Caution: Sample Sizes and Margin of Error (MOE)

Caution should be used when interpreting a statistic based on small sample sizes or when the Margin Of Error (MOE) is large relative to the estimate. The MOE is a measurement of the accuracy of the statistic. We highly recommend that you indicate the sample size and MOE when reporting a statistic.

Go to Glossary for more about Margin of Error (MOE) (/glossary.cfm?q_id=269&view=true)
Go to Glossary for more about sample size (/glossary.cfm?q_id=219&view=true)

Definition of

Definition of Any Disability
The ACS definition of disability is based on six questions. A person is coded as having a disability if he or she or a proxy respondent answers affirmatively for one or more of these six categories.

**Hearing Disability** (asked of all ages): Is this person deaf or does he/she have serious difficulty hearing?

**Visual Disability** (asked of all ages): Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?

**Cognitive Disability** (asked of persons ages 5 or older): Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?

**Ambulatory Disability** (asked of persons ages 5 or older): Does this person have serious difficulty walking or climbing stairs?

**Self-care Disability** (asked of persons ages 5 or older): Does this person have difficulty dressing or bathing?

**Independent Living Disability** (asked of persons ages 15 or older): Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor’s office or shopping?

Go to Frequently Asked Questions for more on defining disability. (/faq.cfm#Q3)

Go to Glossary for more terms and definitions. (/glossary.cfm)

**Source**

These statistics were calculated by the Cornell University Employment and Disability Institute using the U.S. Census Bureau's 2013 American Community Survey (ACS) Public
Use Microdata Sample (PUMS) data.
Go to Data Sources for more about the ACS (/sources.cfm?
n=3#acs)

**Suggested Citation**

We suggest the following citation when using these statistics:


Statistics : Search : Description : Table
Pathways to Employment

General Information
Pathways to Employment is a program designed to support low-income teens and young adults with disabilities in Delaware who want to work. The program helps participants get prepared for work, find jobs, and succeed in the workplace.

Eligibility
In order to participate in the Pathways to Employment program an individual must:

- Want to work
- Be aged 14 to 25
- Be enrolled in Medicaid and meet related financial eligibility criteria
- Be in one of the targeted disability groups (persons with intellectual disabilities; autism spectrum disorders; visual impairments; or physical disabilities)*
- Meet certain disability-specific functional criteria

* People with mental health support needs are served by a similar program called PROMISE.

Services
Pathways to Employment participants receive employment-related services to meet their individual needs.

Services available through Pathways to Employment include:

- Employment Navigator
- Career Exploration and Assessment
- Supported Employment - Individual
- Supported Employment - Small Group
- Benefits Counseling
- Financial Coaching
- Non-Medical Transportation
- Personal Care (including a self-directed component)
- Orientation, Mobility, Assistive Technology

For a brief description of each service, visit the Pathways to Employment - Services page.

Learn More
Follow the links below to get more detailed information about Pathways to Employment.

- Pathways to Employment Brochure
- Pathways to Employment Flyer
- Pathways to Employment Presentation
- Pathways to Employment State Plan Amendment (approved by Centers for Medicaid and Medicare Services effective 1/1/15)

How to Enroll or Make a Referral
To enroll in Pathways to Employment or to refer someone who you think might benefit from the program, contact the Delaware Aging and Disability Resource Center (ADRC).

Information for Service Providers

To enroll as a service provider, please visit the Pathways to Employment - Information for Service Providers page.
PROMISE

What is PROMISE?
The PROMISE program (Promoting Optimal Mental Health for Individuals through Supports and Empowerment) will target individuals with behavioral health needs and functional limitations to offer an array of home and community-based services (HCBS) that are person-centered, recovery-oriented, and aimed at supporting beneficiaries in the community. PROMISE will help improve clinical and recovery outcomes and reduce unnecessary institutional care through better care coordination, and thereby also reduce the growth in overall program costs.

PROMISE will provide a variety of community based services such as:

- Care Management
- Individual Employment Supports
- Short-Term Small Group Supported Employment
- Financial Coaching
- Benefits Counselling
- Peer support
- Non-Medical Transportation
- Community-Based Residential Supports Excluding Assisted Living
- Nursing
- Community Psychiatric Support and Treatment
- Psychosocial Rehabilitation
- Respite
- Independent Activities of Daily Living/Chore
- Personal Care
- Community Transition Services

For a description of each of the services listed above, please view the PROMISE Services Presentation.

PROMISE Public Hearings
In September of 2014, the Division of Substance Abuse and Mental Health (DSAMH), along with the Division of Medicaid and Medical Assistance (DMMA) held three public hearings regarding the 1115 Waiver Amendment (PROMISE). The goal of the PROMISE program (Promoting Optimal Mental Health for Individuals through Supports and Empowerment) is to improve clinical and recovery outcomes and reduce unnecessary institutional care through better care coordination, and thereby also reduce the growth in overall program costs. During the public hearings, an overview of PROMISE was presented to those in attendance, and as a result the state received and responded to numerous questions and comments from the public regarding the PROMISE program.

For more information on PROMISE and how to qualify, please view the PROMISE Brochure.

Provider Information

The Division of Substance Abuse and Mental Health will work with qualified mental health providers to deliver home and community-based, person-centered, recovery-oriented services under the PROMISE program for Delaware residents suffering from severe and persistent mental illness and substance use disorders.

New Provider Information/Training:
- PROMISE Training Requirements
- PROMISE Training Curriculums
- PROMISE Training Calendar
- New Provider Implementation Checklist
- Find Information on Preadmission Screening and Resident Review (PASRR)

Want to become a PROMISE provider in Delaware? Contact the Provider Relations Unit at (302) 255-9463 for information!

Provider Billing:
- PROMISE HCBS Service Certification and Reimbursement Manual-Draft

Contact Information:
- Contact the Eligibility and Enrollment Unit (EEU)
- PROMISE Provider Directory

You may also contact the DSAMH Provider Relations Unit with any additional questions or concerns at (302) 255-9463 or by email at DSAMHPromise@state.de.us.

Beneficiary Information
- Contact the Eligibility and Enrollment Unit (EEU)
- Find a Nearby PROMISE Provider
- Find Treatment Services

You may also contact the DSAMH Office of Consumer Affairs at (302) 255-9421 with any questions or concerns.

Need Immediate Help?
- Contact the Crisis Intervention Unit

Last Updated: Monday February 08 2016
Tax Credits for Hiring Disabled Workers

By Madison Garcia
ehow Contributor

Under the Americans with Disabilities Act, any employer with more than 15 employees must provide reasonable accommodation for disabled individuals. Although it's a federal requirement, businesses can still get federal tax credits for hiring disabled workers and restructuring the workplace to accommodate them. Tax deductions and state tax credits are also available.

Work Opportunity Credit

The federal government offers a federal tax credit for employers that hire new employees out of a targeted group that includes disabled individuals. In order to qualify for this credit, the employee must be certified as disabled by the appropriate governmental agencies. The credit offers employers up to 40 percent of the first $6,000 of wages given to new disabled employees. To claim the credit, the employer should complete IRS Form 5884, Work Opportunity Credit, and include it with the annual business tax return.

Disabled Access Tax Credit

Even if a business didn't hire any new disabled employees, it can still get a tax credit for providing or improving disabled access. The Disabled Access Credit is available to small businesses that earn less than $1 million and have fewer than 30 full time employees. Eligible expenditures include removing accessibility barriers, providing interpreters or audio materials for the hearing-impaired, providing readers for the visually-impaired, and purchases or improvements on any devices for disabled individuals. The maximum annual credit is $5,000. Businesses can claim the tax credit by completing IRS Form 8826, Disabled Access Credit, and attaching it to the business return.

Barrier Removal Tax Deduction

Although large businesses may not qualify for the Disabled Access Credit, they can still take advantage of the Barrier Removal tax deduction. Normally, a business must capitalize any structural improvements to buildings and vehicles and depreciate them over the assets' lives. However, if the improvement is related to improving accessibility for the elderly or disabled, it can deduct the cost immediately. The maximum amount a business can deduct each year is $15,000.
State Tax Incentives
Along with federal tax credits, many states offer tax incentives for costs connected to disabled individuals. For example, businesses based in Maryland can get a state tax credit for hiring employees with disabilities. Employers can get a maximum credit of $1,800 for employee wages the first year of employment and up to $1,200 in the second year. Maryland also offers a credit up to $600 the first year and $500 the second year for providing transportation and childcare expenses for disabled individuals. New York offers a similar program that provides up to $2,100 in state tax credits.
State Rehabilitation Council for the
Division of Vocational Rehabilitation

State Rehabilitation Council of Delaware

DVR
Linking Ability & Business

2015 Annual Report
DVR RECORDS AND ACHIEVEMENTS

The Division of Vocational Rehabilitation set a new record for successful employment outcomes in FY 2015, increasing the number of individuals who were successfully employed by 92 over the previous year for a total of 1,138! Among the individuals who achieved successful employment outcomes, 1070 (94 %) individuals had significant disabilities and 355 (31%) were individuals who had received Transition services.

![Bar chart showing successful outcomes, successful outcomes with significant disabilities, and successful transition outcomes from 2011 to 2015.]

This chart indicates the five-year trend in the number of total successful DVR outcomes, successful outcomes for individuals with significant disabilities, and successful outcomes for individuals who received transition services.

Average Hourly Wage

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>Average Hourly Wage</th>
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<tbody>
<tr>
<td>FY 2015</td>
<td>$10.50</td>
</tr>
<tr>
<td>FY 2014</td>
<td>$10.50</td>
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<tr>
<td>FY 2013</td>
<td>$10.50</td>
</tr>
<tr>
<td>FY 2012</td>
<td>$10.50</td>
</tr>
<tr>
<td>FY 2011</td>
<td>$9.50</td>
</tr>
</tbody>
</table>

![Bar chart showing average hourly wage from FY 2011 to FY 2015.]

This chart indicates the five-year trend for the average hourly wage of all individuals who were successfully employed through DVR.

During FY 2015, DVR began formal implementation of Pre-Employment Transition Services as required under the Workforce Innovation and Opportunity Act. The division solicited bids for community partners to offer summer programs that would offer transition students exposure to employment expectations and experience in employment situations. DVR funded 11 programs statewide that offered services to over 100 transition students. The feedback from these programs was overwhelmingly positive, and DVR is expanding Pre-Employment Transition Services in FY 2016.
DVR PERFORMANCE REPORT

Successful Rehabilitations: 1,138
   Most Significant Disabilities 357 (31%)
   Significant Disabilities 715 (63%)
   Transition Youth Rehabilitated 355

Total Clients Served: 7,757
   Clients with Most Significant Disabilities 2,614 (34%)
   Clients with Significant Disabilities 4,303 (56%)

New Applicants in FY 2015: 2,861
   Determined Eligible 2,501
   Acceptance Rate 92%

New Transition Students: 782
   Transition Students/Youth Served 2,284

Average Hourly Wage for FY 2015 closures:
   All closures $10.54
   Transition $10.00
   Supported Employment $8.61
   Adults (not TR or SE) $11.15

Individuals in Delayed Status at the end of FY 2015 37
BILL: SENATE BILL NO. 186
SPONSOR: Senator Townsend
DESCRIPTION: AN ACT TO AMEND TITLE 14 AND TITLE 29 OF THE DELAWARE CODE RELATING TO SCHOOL TAXES.

ASSUMPTIONS:

1. This Act is effective upon signature of the Governor.

2. This Act will create the Disabled Veteran School Tax Refund Fund whereby a resident who is a disabled veteran, regardless of age, and owns and occupies a principal residence, will receive a refund against school property taxes depending on his/her disability rating. A qualified individual with a disability rating of 10% to 20% may receive a refund of $200; a rating of 30% to 40% may receive a refund of $350; and a rating of greater than 60% may receive a refund of $500.

3. An individual qualified to receive the Disabled Veteran School Tax Refund and the Senior School Property Tax Refund will only receive one refund from either program, but not both.

4. There are an estimated 4,346 disabled veteran property owners under the age of 65 who would be eligible to receive the Disabled Veteran School Tax Refund pursuant to this Act. Below is the methodology used to develop this estimate based on the assumptions as indicated:

   A. Number of Veterans in Delaware Receiving Disability Compensation: 11,404
   B. Homeowner Rate in Delaware: 72.5%
   C. Estimated Disabled Veterans Owning a Home: 8,268 (A X B = C)
   D. Percentage of Delaware Veterans 65 or older: 47.4%
   E. Estimated Disabled Veterans 65+ Receiving Sr. Property Credit: 3,922 (C X D = E)
   F. Estimated Disabled Veterans Eligible for Disabled Veteran Refund: 4,346 (C – E = F)

5. Based on information from the Department of Finance, the estimated average Senior School Property Tax Credit is $368 and this value is assumed as the average refund for the Disabled Veteran School Tax Refund.

6. This Act establishes the Disabled Veteran School Tax Refund Fund at $3,000,000. However, the projected impact of the program is less than the $3,000,000 identified in the Act.

Cost:

Fiscal Year 2017: $1,599,300
Fiscal Year 2018: $1,599,300
Fiscal Year 2019: $1,599,300

(Amounts are shown in whole dollars)

Office of Controller General
March 01, 2016
MSJ:MSJ
0271480028
How Do Disability Ratings Work for Veterans Benefits?

The Department of Veterans Affairs uses a disability rating system to determine the amount of compensation provided to disabled Armed Forces veterans.

Make the most of your claim. We’ve helped 225 clients find attorneys today.

Has the applicant previously applied for social security disability? [Step 1 of 8]

--Select an answer--

by Jean C. O'Neill (/law-authors/jean-c-oniell.html), Contributing Author

Veterans of the United States Armed Forces with disabilities connected to, or aggravated by, active service may be eligible for veterans disability benefits. After the veteran has applied for benefits, the Department of Veterans Affairs (VA) evaluates the medical evidence and determines whether or not the veteran qualifies for benefits. The VA then assigns the disability a rating level, which dictates the amount of monetary compensation the veteran will receive due to his disability or disease.

Disability Ratings

In order to qualify for veterans disability benefits, certain criteria must be met. (See our article on filing for veterans disability benefits [http://www.disabilitysecrets.com/resources/disability/veterans-...](http://www.disabilitysecrets.com/resources/disability/how-do-disability-ratings-work-veter... 3/30/2016)}
If the VA determines that a the veteran qualifies for disability benefits, it assigns the disability a rating to signify the extent of the disability or disease. The disability rating represents the "average detriment to earning capacity" resulting from the disability or disease.

The ratings are assigned in 10% increments, ranging from 10% to 100% disabled. A higher disability rating indicates the veteran has a more severe disability, and therefore receives a higher monthly compensation payment. For example, under the current wartime rates for veterans without dependents, a 10% disabled veteran is entitled to receive $123 per month, a 50% disabled veteran is entitled to receive $770 per month, and a 100% (or totally) disabled veteran is entitled to receive $2,673 per month. Generally, the compensation rates are subject to an annual cost of living increase.

The law also provides for special compensation rates for many enumerated, more serious disabilities or injuries. Injuries such as loss of a single hand or foot, blindness or severe injury to one eye, loss of ability to speak, and deafness, to name a few examples, are entitled to an increase of $96 per month per injury (maximum $4,667 per month) above the base compensation rate. Loss of both hands, both feet, blindness in both eyes, or a permanent bedridden state entitles the veteran to $3,327 compensation per month. The law also lists several other disabilities that may merit higher, specific payments. Additionally, the statute allows for the Secretary of the VA to approve higher payments for more severe disabilities if necessary, with a maximum of $4,667 per month.

Rating for Multiple Disabilities

When a veteran has more than one disease or disability, the disability ratings are not simply added together (for example, a 40% disability rating plus a 20% disability rating does not equal a total 60% disability rating.) Instead, a formula is used to determine the total disability rating level for multiple disabilities. First, the disabilities are ranked from most to least severe. Then, it is determined what percentage of efficiency the veteran retains after the first, most severe disability. For example, if the veteran's most severe disability is rated at 40%, he is still 60% efficient.

After that, the second most severe disability is considered. That second disability rating is applied to the vet's remaining efficiency. For example, if the veteran after the first disability has a remaining 60% efficiency, and his second most severe
disability has a 20% disability rating, then 20% of the 60% efficiency is calculated – in this case, 12%, and that number is added to the original disability rating (40% plus 12% equals 52% disabled).

The new disability rating is rounded up or down to the closer 10% increment. In the example above, the 52% rating would be rounded down to a 50% disability rating, and that veteran would be considered 50% disabled.

Reexamination and Changes to Disability Ratings

Once a disability rating is assigned, it may be subject to change in certain circumstances. For example, the VA may require medical re-examination of the veteran six months after leaving service, and then again between two and five years later. The VA does this to verify either the continued existence of or the current severity of a disability, particularly in cases where it is likely that a disability has improved, or if evidence indicates there has been a material change in a disability, or that the current rating may be incorrect. In such cases it is possible that the rating and benefits may be reduced or discontinued.

Re-examination would not likely occur in cases where the disability was determined at the outset to be permanent, in cases where the disability has not sustainably improved in five years, or in cases where the veteran is older than 55 years of age and his rating would not be changed by reexamination.

A veteran receiving benefits may file VA Form 21-4138 to request a new evaluation if he develops a new disability or disease connected to his service, or if he finds his condition worsening. The VA may then increase the veteran's disability rating and therefore increase the monthly compensation.

When Benefits Cannot Be Reduced

The VA cannot reduce a disability rating for a veteran with a 100% disabled rating unless there is a medical examination or evidence of ability to maintain employment for 12 consecutive months that shows “material improvement” in his physical or mental condition.

If a veteran has been deemed to have permanent and total disability and has been receiving disability benefits for twenty years or more, his benefits cannot be reduced. If the veteran's disability is less than permanent and total, and the
veteran has been receiving disability benefits for twenty years or more, and upon re-examination by the VA the veteran's disability rating is lowered, the amount of compensation will not drop below the original level. For example, if the veteran has been deemed to be 40% disabled for a period of twenty continuous years or more and is then re-evaluated to be only 30% disabled, the amount of his benefits will not drop below the 40% compensation rate.

Learning More

For information on applying for benefits, and how veterans disability benefits relate to Social Security disability benefits, see our section on veterans benefits (http://www.disabilitysecrets.com/topics/social-security-disabled-veterans). If you disagree with your disability rating and wish to challenge it, arrange a consultation with a disability lawyer certified with the VA (http://www.disabilitysecrets.com/consultation/request_details?).

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Tax Exemptions

Partial tax exemptions are available for some taxpayers. Those who are disabled or over 65 may be eligible, depending upon income levels. Exemptions for non-profit organizations and for agricultural property are also available, provided conditions are met. The exemption application provides more complete information on eligibility requirements.

Applications
- Disability and Over-65 Exemption Requirements
- Disability Exemption
- Over-65 Exemption
- Farmland Exemption
- General Exemption
- Senior School Property Tax Credit Application
- Sewer Clean-out Reimbursement Exemption
- Wilmington Tax Exemption
Senior & Disability Property Tax Discounts
Qualification & Deadline Requirements

Over 65 Exemption Qualifications:

- Applicant must be 65 years of age before July 1st of the year you wish to apply
- Must be your primary residence and you must have been living in the State of Delaware for a period of 3 years prior to October 1st of the preceding year of application.
- Must be an owner of record.
- Assessed value of the property cannot exceed $125,000. For those whose value exceeds the $125,000 limit, and their Adjusted Gross Income (A.G.I.) less taxable Social Security does not exceed $3,000, the State Senior Property Tax Exemption of $5,000 will apply.
- Applicant’s household A.G.I. from Federal Forms 1040 or 1040A from the preceding calendar year must be no greater than $50,000 (single or married) not including Taxable Social Security or Railroad Retirement (Tier 1) to qualify for the County Property Tax reduction. In order to receive the Reduction on both County and School, the limit is as follows: Single-$15,000 Married $19,000 not including Taxable Social Security, or Railroad Tier 1 Retirement.
- County Tax, School Tax and Sewer service charge accounts with New Castle County must be current; or the applicant must be actively enrolled and making payments according to a schedule set and approved by the Finance Department.
- Application must be signed and dated. (No photocopied applications allowed.)

Deadlines

- Applications are due in the Office of Property Assessment by June 1st
- Exemptions become effective July 1st
- If an applicant that has been approved and was receiving the exemption on or before July 1, 2007 at their previous residence, and has moved to another residence in New Castle County, an application of transfer must be filed including proper income and residency documentation with the Office of Property Assessment within 30 days of settlement in order to continue receiving a reduction on future bills at the new residence

Benefits-(applicants approved July 1, 2007 and before):

- Sewer Service charge – receive 50% off that charge, or the minimum bill charge ($36), whichever is higher.
- County Tax – Assessed value reduced up to $50,000
- School Tax – Assessed value reduced up to $32,000
• Sewer Lateral Cleanout – they receive a reimbursement of up to $75, once every 12 months for charges incurred for sewer lateral clean-out.

Benefits-(applicants approved July 1, 2008 and thereafter):

• Sewer Service charge – receive 50% off that charge, or the minimum bill charge ($50), whichever is higher.
• County Tax – Assessed value reduced up to $32,000 (for A.G.I. $50,000 or less, Household Income)
• School Tax – They receive a reduction in their assessed value of up to $32,000 (for A.G.I. of $19,000 or less for a married couple and $15,000 or less for a single person)
• Sewer Lateral Cleanout – They may be eligible to receive a reimbursement of up to $75 once every 12 months, of charges incurred for sewer lateral clean-out for those receiving the exemption.

Disability Exemption Qualifications:

• Property must be applicant’s primary residence and applicant must have been living in the State of Delaware for a period of 3 years prior to October 1st of the year of application.
• Must be an owner of record.
• Applicant must provide their current Social Security Award Notification, or have their treating physician sign the application attesting to the stated disability (must be original signature, no photocopies allowed)
• Applicant’s A.G.I. from Federal 1040 or 1040A form for the preceding calendar year must be $50,000 or less in household income (single or married) not including Railroad Retirement Tier 1 or Taxable Social Security.
• County Tax, School Tax, and Sewer Service Charges must be current with New Castle County, or the applicant must be actively enrolled in a payment plan according to a schedule set-up and approved by the Finance Department.

Deadlines:

• Original Exemption applications must be received no later than June 1st.
• Exemption becomes effective July 1st.
• If an applicant has been approved for this exemption on or before July 1, 2007, and moves to a new property within New Castle County and files an application of transfer within 30 days of settlement including proper income and residency documentation with the Office of Property Assessment, the exemption will be applied to their new primary residence.
Benefits- (Applicants approved prior to July 1, 2008):

- Sewer Service Charge – receive 50% off that charge, or the minimum bill charge ($50), whichever is higher.
- County Tax – They receive a reduction in their assessed value of up to $40,000. For loss of limbs or loss of limbs requiring home to be equipped with special fixtures, an additional $42,000 may be added to a maximum of $82,000.
- School Tax – They receive a reduction in their assessed value of up to $32,000. For loss of limbs or loss of limbs requiring home to be equipped with special fixtures, an additional $42,000 may be added to a maximum of $74,000.
- Sewer Lateral Cleanout - They may be eligible to receive a reimbursement of up to $75 once every 12 months, of charges incurred for sewer lateral clean-out for those receiving the exemption.

Benefits- (Applicants approved July 1, 2008 and thereafter):

- Sewer Service Charge – receive 50% off that charge, or the minimum bill charge ($50), whichever is higher.
- County Tax – They receive a reduction in their assessed value of up to $32,000. For loss of limbs or loss of limbs requiring home to be equipped with special fixtures, an additional $42,000 may be added to a maximum of $74,000.
- School Tax – They receive a reduction in their assessed value of up to $32,000. For loss of limbs or loss of limbs requiring home to be equipped with special fixtures, an additional $42,000 may be added to a maximum of $74,000.
- Sewer Lateral Cleanout - They may be eligible to receive a reimbursement of up to $75 once every 12 months, of charges incurred for sewer lateral clean-out for those receiving the exemption.

- Please Note: If the disability is Armed Forces Related, the taxpayer may receive an additional reduction of $5,000 off the assessed value of the residence for both County and School Taxes.
- Regarding Married Couples: Only one Exemption per household is allowed ex: One spouse is already receiving the discount and the remaining spouse turns 65 or becomes disabled, you can not get another discount in addition to the existing discount.
State of Delaware – Senior School Tax Credit:

- Applicant must be 65 years of age prior to July 1st of the year in which they wish to apply and must provide a legible copy of their unexpired Delaware Driver’s License or State of Delaware issued I.D.
- The property must be the applicant’s primary residence, and must be an owner of record.
- The applicant must have been living in Delaware a minimum of 3 years prior to April 30th of the year of application.
- The application must have the original signature (no photocopies)
- Tax and sewer accounts with NCC must be current. (No payment plan authorized for approval.)

Deadlines:

- Applications must be received by New Castle Treasury Department no later than April 30th.
- The Credit becomes effective July 1st of the year of application.

Benefits:

- School Tax, a credit of 50% of the School Tax line item, not to exceed a credit amount of $500
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

White 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.

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."
Delaware's heroin babies: Starting life in withdrawal

Adds Nancy Fosyny, 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
Delaware's heroin babies: Starting life in withdrawal

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 8-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, 360,000 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 10,800 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.
Delaware's heroin babies: Starting life in withdrawal

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 opiod 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."
Delaware's heroin babies: Starting life in withdrawal

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."
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 Tamya Braxton, a New Expectations client who was cuddling her two-month-old son, Makai Brown, born while Braxton 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
Delaware's heroin babies: Starting life in withdrawal
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.
(Phrase: JENNIFER CORBETT/THE NEWS JOURNAL)
Delaware newborn addictions rise, triggering new hospital rules

Newborn addictions rise, triggering new hospital rules

1:14 a.m. EST January 18, 2016

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.

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.

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."
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.

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Read or Share this story: http://delonline.us/1UzoQKT
Editorial: To save the kids, treat the addicted parents

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

At first glance, the deaths of kids like Aidan Hundleby and Autumn Milligan (story/news/local/heroin/2016/03/04/delaware-falling-heroin-babies/80990476/) 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-sharing-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 9,677 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's-deadly-impact/78399492/), 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 overpowers 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

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 provide a quieter environment," said Dr. David Paul, chair in Pediatrics at Christiana. Babies born sensitive to light and sound than healthy infants; the constant beeping and foot-shuffling of a neonatal intensive care unit is almost too much 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 health center, an 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/pubmed/25963059) to relieve the pain of withdrawal from opiates, and within three to six weeks, also draw down the dose of morphine. The drug also prevents 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 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 put 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 risk, but 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, shows 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 after the 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


DELAWAREONLINE

Raising awareness for fetal alcohol syndrome


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 Buckalew, 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) 983-6775, or Twitter @JamesFisherTNJ or jfisher@delawareonline.com.

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More treatment key for addicted moms

Jon Rinaldi and Katherine Parra, The News Journal 6 p.m. EST March 4, 2016

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 her child, her partner overdosed and died. Consumed by grief, Rybinski turned to heroin and cocaine during the last five months of her pregnancy.

After she gave birth to her son James April 6, 2014, at Christiana Care's Wilmington, she was clean.

She said the Division of Family Services told her that they had to take custody of him because they 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, 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 if 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, like Rybinski, have long lamented Delaware's lack of residential treatment options. Many people have to wait days or even weeks to get into treatment.

That was the case with Rybinski. She tried to get admitted to rehabs in Maryland and Pennsylvania before turning back to her doctor for help.

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 treatment and case management. In that same period, 198 babies were born and 187 were born free of illicit drugs, data from the program. About 145 were delivered to full term and 133 were born within a healthy weight.

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 Newarks.

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.
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 A2ack 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.

“Medicaid 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 DOJ. DFS terminated her parental rights.

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.

“T 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,” her 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 forget what my purpose was.”

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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 "Aiden’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 patchwork 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 (http://newslocal/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 whereabouts 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.

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 duffle 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 talks about the children born with addictions. (Photo: JENNIFER CORBETT/THE NEWS JOURNAL)

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/heroindelaware/2016/03/04/delaware-failing-heroin-ba... 3/11/2016
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 Aidan 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.
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 Tanla Cullay, 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-trippering-now-hospital-rules78661632/ 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.

"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.

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 Aiden’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 Harrsontown is a white ceramic tile, with “Aiden Ryder” printed in black. A heart stands in for the the dot over the “i” in Aiden, and tiny blue footprints decorate either side of Aiden’s date of birth and death — 02-19-15 to 09-22-15 (story/news/crime/2015/12/11/mother-father-charge-killing-8-month-old-son/771451841).

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.

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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.

Don’t miss a thing

MEMORANDUM

DATE: March 24, 2016

TO: The Honorable Members of the Delaware General Assembly

FROM: Robert D. Overmiller, Chairperson
GACEC

RE: House Bill No. 214 (Nurse Workplace Violence Protection)

The Governor’s Advisory Council for Exceptional Citizens (GACEC) has reviewed House Bill No. 214, which will upgrade an assault on a nurse performing a work-related duty to a second degree assault or class D felony. Council would like to share the following observations.

Under current law, if a person intentionally causes “physical injury” to a member of the general public, the crime is a misdemeanor A punishable by up to one year in prison. See 11 Del.C. Secs. 611 and 4206. There is a special statute [11 Del.C. Sec. 612] which elevates the misdemeanor to a felony D if a person intentionally causes “physical injury” to a nurse “while [the nurse] is rendering emergency care”. The penalty for a class D felony is up to eight years in prison. See 11 Del.C. Sec. 205(b). The definition of “physical injury” is “impairment of physical condition or substantial pain”. See 11 Del.C. Sec. 222(23). Therefore, the current law elevates the maximum one year prison term to a maximum eight year term for an assault on a nurse providing emergency care with no significant injury apart from “pain”. House Bill No. 214 would expand the application of the eight-year prison term to nurses in non-emergency contexts, i.e., while “performing a work-related duty” (lines 17-18). While well intentioned, the concern of the Council is that authorizing a prison term not double, triple, or quadruple but eight times in length for an assault resulting only in some pain seems disproportionate to the offense. One compromise would be to elevate the offense against a nurse to a felony F or G which carry two and three year prison terms respectively.

Council suggests that policymakers consider the unintended consequences of this legislation. The bill could easily result in prosecution of patients with compromised capacity at the time of the alleged crime. For example, individuals with urinary tract infections may display symptoms similar to mental illness. Individuals with an extreme fear of needles may defensively strike out
at a nurse attempting to perform an injection. An elderly patient may strike out defensively at a nurse attempting to impose wrist or mechanical restraints on the patient to prevent the patient from removing tubes or aggravating wounds. Medications or a high fever may compromise executive functioning and self-control. A patient who does not speak English may defensively try to block an injection or push a nurse away out of a lack of understanding. A patient may experience involuntary movements or seizures which a nurse could misinterpret as voluntary acts of aggression. A patient with an undiagnosed traumatic brain injury (TBI) may strike out as a function of brain injury. While well intentioned, the unintended consequences of this bill may be to unnecessarily “criminalize” a large number of vulnerable patients and Council reiterates that the penalties seem extreme in relation to the offense.

Thank you for your time and consideration of our observations. Please feel free to contact me or Wendy Strauss should you have any questions.
COMMITTEE REPORT

HB 214

Sponsor: Keeley

Long Title: AN ACT TO AMEND TITLE 11 OF THE DELAWARE CODE RELATING TO ASSAULT.

Committee: PUBLIC SAFETY & HOMELAND SECURITY

Number of Committee Members: 11

Date of Report: 03/23/2016

Committee Vote: Favorable: 2 On Its Merits: 5 Unfavorable: 0

Purpose of the Bill: Currently, for an assault to rise to the level of assault in the second degree against a nurse, the nurse must be rendering emergency care. This bill raises the level for an assault on a nurse performing a work-related duty to the second degree.

Committee Findings: The committee found that the language in this bill needs to be reworked in order to address punishments for individuals who are mentally handicapped.
§ 611 Assault in the third degree; class A misdemeanor.

A person is guilty of assault in the third degree when:

(1) The person intentionally or recklessly causes physical injury to another person; or

(2) With criminal negligence the person causes physical injury to another person by means of a deadly weapon or a dangerous instrument.

Assault in the third degree is a class A misdemeanor.

§ 4206 Sentence for misdemeanors.

(a) The sentence for a class A misdemeanor may include up to 1 year incarceration at Level V and such fine up to $2,300, restitution or other conditions as the court deems appropriate.
§ 4205 Sentence for felonies.

(a) A sentence of incarceration for a felony shall be a definite sentence.

(b) The term of incarceration which the court may impose for a felony is fixed as follows:

(1) For a class A felony not less than 15 years up to life imprisonment to be served at Level V except for conviction of first degree murder in which event § 4209 of this title shall apply.

(2) For a class B felony not less than 2 years up to 25 years to be served at Level V.

(3) For a class C felony up to 15 years to be served at Level V.

(4) For a class D felony up to 8 years to be served at Level V.

(5) For a class E felony up to 5 years to be served at Level V.

(6) For a class F felony up to 3 years to be served at Level V.

(7) For a class G felony up to 2 years to be served at Level V.

(c) In the case of the conviction of any felony, the court shall impose a sentence of Level V incarceration where a minimum sentence is required by subsection (b) of this section and may impose a sentence of Level V incarceration up to the maximum stated in subsection (b) of this section for each class of felony.

(d) Where a minimum, mandatory, mandatory minimum or minimum mandatory sentence is required by subsection (b) of this section, such sentence shall not be subject to suspension by the court.

(e) Where no minimum sentence is required by subsection (b) of this section, or with regard to any sentence in excess of the minimum required sentence, the court may suspend that part of the sentence for probation or any other punishment set forth in § 4204 of this title.

(f) Any term of Level V incarceration imposed under this section must be served in its entirety at Level V, reduced only for earned "good time" as set forth in § 4381 of this title.

(g) No term of Level V incarceration imposed under this section shall be served in other than a full custodial Level V institutional setting unless such term is suspended by the court for such other level sanction.

(h) The Department of Correction, the remainder of this section notwithstanding, may house Level V inmates at a Level IV work release center or halfway house during the last 180 days of their sentence; provided, however, that the first 5 days of any sentence to Level V, not suspended by the court, must be served at Level V.

(i) The Department of Correction, the remainder of this section notwithstanding, may grant Level V inmates 48-hour furloughs during the last 120 days of their sentence to assist in their adjustment to the community.

(j) No sentence to Level V incarceration imposed pursuant to this section is subject to parole.
(23) "Physical injury" means impairment of physical condition or substantial pain.

(24) "Public transit operator" means a person in control or in charge of a transportation vehicle for public use, in exchange for a fee or charge, offered by any railroad, street railway, traction railway, motor bus, or trolley coach. Specifically excluded are:

a. Transportation to and from any school or school-sponsored event when such transportation is under the regulation of the Department of Education; and

b. Transportation to and from a church, synagogue or other place of worship;

c. Shuttle-type transportation provided by business establishments without charge to customers of the businesses offering such shuttle transportation between fixed termini; and

d. Limousine services.

(25) "Serious mental disorder" means any condition of the brain or nervous system recognized as defective, as compared with an average or normal condition, by a substantial part of the medical profession.

(26) "Serious physical injury" means physical injury which creates a substantial risk of death, or which causes serious and prolonged disfigurement, prolonged impairment of health or prolonged loss or impairment of the function of any bodily organ, or which causes the unlawful termination of a pregnancy without the consent of the pregnant female.
Delaware can lead the way on sentencing law reform

DELAWARE VOICE
KIRSTIN CORNELL

Nationally, lawmakers are revisiting the tough sentencing laws that made the United States the world’s number one jailer. In recent years, voices from the left and the right have joined together in challenging the scale of incarceration. Delaware has engaged similar efforts too, but lags behind the country in downscaling its prison population. This year, state lawmakers have an opportunity to revisit excessive punishment by scaling back the state’s “three strikes” out law.

The growth of incarceration in Delaware resulted from the choices of lawmakers to increase the use and severity of prison sentences. Delaware’s correctional population has grown by more than 207 percent since 1980; taxpayers spend more than $32,900 to incarcerate each prisoner. According to the Delaware Criminal Justice Council more than 500 prisoners were serving life terms at the end of 2015.

Delaware legislators are revisiting the state’s harsh sentencing frameworks with Senate Bill 163. The modest proposal would change the statute that governs habitual offenders including eliminating mandatory life in prison for a third criminal conviction. Specifically, under the proposed law a person would be declared a habitual criminal after being convicted of a third violent felony or a fourth felony of any kind. The bill is retroactive and would allow for a sentencing modification for persons convicted under the old law.

State law enforcement leaders like Attorney General Matt Denn have called for changes to the “three-strikes” law, specifically challenging life in prison as a mandatory sentencing option.

Any serious crime, is a crime too many. But doing something and solving the problem are not always the same. Despite their intent, mandatory minimum laws like “three strikes” do little to reduce crime. They do, however, help drive growth in incarceration and demand substantial spending on a state’s prison system. Those are among the key reasons there is growing consensus to reform harsh sentencing laws and restore judicial discretion to judges.

More important, after years of experience, legislators and policy-makers across the country are recognizing these one-size-fits-all laws don’t increase public safety. In California -- voters revisited their “three strikes” law year and allowed for resentencing. Legislators in Mississippi scaled back state’s mandatory sentencing scheme for violent offenses to address prison overcrowding. Last year, Alabama lawmakers revisited that state’s harsh sentencing laws and expanded alternatives to incarceration. This year, New Mexico lawmakers rejected efforts to toughen that state’s “three strikes” laws.

Delaware’s adoption of SB 163 could help move the country even farther. And much more could be done.

In recent years, legislators in Rhode Island and Utah repealed mandatory minimums for certain offenses. Officials in at least 29 states have adopted reforms designed to scale back the scope and severity of their mandatory sentencing policies over the past decade. Criminal justice reform should prioritize law enforcement, judicial and corrections resources towards preventing crime from happening in the first place -- rather than clogging up the system due to a lack of judicial discretion and an inability to imposing criminal penalties that are fair and just.

It is tempting to believe mandatory minimum sentencing and “three strikes” laws will make Delaware safer. But in reality, there is little proof to show that such laws accomplish what the contrary, studies suggest that reformation may actually increase with longer sentences. Officials motivated to improve public safety should prioritize evidence-based practices known to deter crime rather than rely on harsh penalties demonstrated to have little impact on future offending.

Revisiting harsh sentencing laws will recognize that the state’s rate of incarceration has produced diminishing returns for public safety. Scaling back sentencing laws retroactively should help to control the prison population and free up resources.

Those resources could be directed into interventions known to reduce crime like quality education, health care, and job training programs.

Kirstin Cornell works with the Delaware Center for Justice, and Nicole Porter is with The Sentencing Project.
Prison reforms protect public safety

Sen. Bonini's opinion regarding the habitual offender reform bill passed by a bipartisan majority in the Delaware State Senate illustrated two unfortunate traits of current politics: misinformation and demonization.

Both merit response.

To correct the facts, the intent of Senate Substitute 1 to Senate Bill 163 is to address some irrational and disproportionate minimum mandatory jail sentences that have been imposed on those designated habitual offenders under Delaware's law. Under current law, many people who burglarize houses receive the same minimum mandatory sentences as people who commit homicides. And some people who have committed their first violent felony receive minimum mandatory sentences of decades in jail. Certainly, many offenders should receive long jail sentences – including those who have committed crimes such as carjacking and rape mentioned by Sen. Bonini. But the disproportionate sentences deserve discussion.

Under the bill, everyone who is considered a "habitual offender" currently will remain a habitual offender, subject to up to life in prison. And with the exception of some drug offenses, everyone who receives a minimum mandatory jail sentence now will continue to receive a minimum mandatory jail sentence.

However, rather than every person who has committed three violent felonies receiving mandatory life in prison, the mandatory sentences will be based on the seriousness of the crime. If the third violent felony is first degree rape, to use Sen. Bonini's example, the minimum mandatory sentence will still be life. But if it is first degree burglary, the minimum sentence will be fifteen years – though a judge will always be able to impose up to life in prison. For habitual offenders who have committed only one violent felony, they will receive lower minimum mandatory sentences than they currently receive – but again, a judge will always be able to impose up to life in prison.

It is only fair that changing the sentencing law going forward means the state should give some consideration to those sentenced under the old law. Under SS 1 to SB 163, a limited number of current inmates whose specific situations match the changes in the law will be able to ask a court to revisit their sentences once they have served the new minimum sentences for their crimes. Contrary to the implication in Sen. Bonini's article, no one will receive an automatic change to their sentence; no jail doors will automatically swing open.

Once they have served any otherwise applicable minimum sentence, inmates can ask to appear before a judge. The Attorney General's office, correctional officials and victims will all weigh in. The judge will have to review a current assessment of the risk the inmate poses to the community, and the judge will have to make a record of the reasons for any change he or she may make in the sentence. The petition process is designed to ensure that public safety is not jeopardized. Moreover, the first set of petitions would be from inmates serving time for drug offenses, followed by inmates serving time for property offenses. Long before any person who has harmed another person is able to file a petition, we will be able to see if the courts are handling these petitions responsibly – we are confident that they will, but if not, we will be the first ones to ask the legislature to change this part of the law.

The state has always had provisions that allowed it to review the sentences of current inmates. Since 1897, the state has had a Board of Pardons that could recommend commutations of sentences to the governor. For decades, the state has had a law that allows the Department of Correction to petition the court to modify the sentences of current inmates. The provisions in SS 1 to SB 163 allowing for limited sentence reviews are an extension of longstanding practice in Delaware.

Unfortunately, Sen. Bonini – who heard all this when the bill was presented to the Senate – has chosen to demagogue the issue and impugn the motives of those seeking to impart what they see as some fairness to the system. Such demonization is not necessary or typical. Sen. Bonini sponsored a bill in 2010 (SB 187) that allowed murderers on death row to bypass the Board of Pardons in pursuit of a gubernatorial commutation. He voted against legislation in 2014 (HB 408) to ensure the solvency of the state's victim compensation fund. He voted against a bill in 2012 making home invasion a separate crime (HB 277). We recall no one suggesting he was for condoning murderers, punishing crime victims, or approving of home invasions.

We have disagreed on criminal justice issues in the past without denigrating one another, and a return to respectful, fact-based dialogue when discussing them would be a service to our state.

Jack Markell is the Governor of Delaware, and Matt Denn is the state's Attorney General.