Office of Disability Prevention for Children Report for Fiscal Year 2018

As Required by Human Resources Code, Section 112.051

Health and Human Services Commission

November 2018
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Executive Summary

The Office of Disability Prevention for Children (ODPC) works to prevent developmental disabilities and seeks to minimize the losses developmental disabilities cause, especially in infants and young children. ODPC prevents disabilities through provider and public education, partnership with other state agencies and stakeholders, and evaluating state efforts to prevent developmental disabilities. Through collaboration with stakeholders and other Health and Human Services (HHS) programs, data analysis, and review of existing research, ODPC has selected five areas of focus:

- Prevention of disabilities caused by prenatal alcohol or substance exposure
- Prevention of disabilities caused by maternal health issues during pregnancy
- Prevention of acquired brain injury in children
- Early identification and diagnosis of disabilities to ensure early intervention and services
- Promotion of mental health wellness for individuals with an intellectual or developmental disability

The Office of Disability Prevention for Children Report for Fiscal Year 2018 details ODPC’s activities in each of these focus areas for fiscal year 2018. The report also includes a review of HHS and Department of Family and Protective Services (DFPS) programs that impact disability prevention in some way. This review and report establishes a framework for future ODPC initiatives.
Texas Human Resources Code, Section 112.051, requires ODPC to submit a biennial report to the legislature detailing the findings of the office, the results of the program and any recommendations for improvements in the delivery of developmental delivery prevention services. This report is due to the Legislature by February 1 of each odd-numbered year.
2. Background

ODPC works to prevent developmental disabilities and seeks to minimize the losses developmental disabilities cause, especially in infants and young children. ODPC spent fiscal year 2018 establishing goals and evaluating the state of disability prevention in Texas.

For the purposes of ODPC, developmental disability is defined\(^\text{1}\) as a severe, chronic disability that:

1. Is associated with a mental or physical impairment or a combination of both
2. Manifests before a person reaches the age of 22
3. Will likely continue indefinitely
4. Requires special interdisciplinary or generic care, treatment, or other lifelong or extended services
5. Results in substantial functional limitations in three or more major life activities. Life activities include:
   a. Self-care
   b. Receptive and expressive language
   c. Learning
   d. Mobility
   e. Self-direction
   f. Capacity for independent living
   g. Economic sufficiency

ODPC is governed by Human Resources Code, Sections 112.041-112.051, and is the successor to the former Texas Office for the Prevention of Developmental Disabilities (TOPDD). Senate Bill 200, 84th Legislature, Regular Session, 2015, abolished TOPDD and its executive committee and transferred the duties to the Health and Human Services Commission (HHSC) effective September 1, 2017. To ensure that these duties were successfully maintained, HHSC established ODPC under the Health, Developmental and Independence Services (HDIS) Department. While ODPC has continued some of the work of TOPDD, the office has been launched with an expanded scope.

\(^{1}\) Human Resources Code, Section 112.042
The activities and goals of ODPC are guided by the duties assigned in statute. To prevent disabilities, ODPC provides professional and client education, partners with other state agencies and stakeholders, and evaluates existing disability prevention initiatives. ODPC has selected five areas of focus in collaboration with stakeholders and other Health and Human Services (HHS) System programs, and through analysis and review of existing research and data.

2 Human Resources Code, Section 112.044
3. Areas of Focus

Levels of Prevention

There are three levels of prevention: primary, secondary, and tertiary. While ODPC’s largest focus is on primary prevention, stakeholders and partners identified several secondary- and tertiary-level issues as areas on which ODPC should focus. ODPC’s five areas of focus therefore address aspects of all levels of prevention.

**Primary prevention** is the prevention of the onset of a disability. ODPC primary prevention efforts aim to reduce the incidence of disability. This could include promotion of wearing a seatbelt to prevent brain injury during a motor vehicle accident or abstaining from drinking alcohol during pregnancy to prevent fetal alcohol spectrum disorders.

**Secondary prevention** is the detection of a disability in its earliest stages and intervening to slow or stop its progression. This could include detecting a developmental delay through a developmental screening and seeking help immediately so the child can get the supports needed to develop the skills and functions typically seen at that age.

**Tertiary prevention** includes interventions implemented to mitigate a disability’s negative impact and prevent secondary conditions. This could include therapies and treatments that support a child’s development and health needs, or adaptive aids that empower a child to find ways to work around their disability.

**Focus Area: Preventing Disabilities Caused by Prenatal Alcohol or Substance Exposure**

ODPC focuses on preventing disabilities caused by prenatal alcohol or substance exposure. Prenatal exposure to alcohol, tobacco, and other substances can cause birth defects and permanent intellectual or developmental disabilities. Although all of these substances can be harmful to a developing fetus, alcohol has the strongest impact. Prenatal alcohol exposure can result in a fetal alcohol spectrum disorder (FASD). A child who has an FASD may have physical birth defects, cognitive deficits, and other neurological issues. These effects can result in a child being unable to live independently, poor school performance, or trouble with law enforcement.
FASD is an umbrella term used to describe the range of neurological and behavioral effects caused by prenatal alcohol exposure. The term refers to specific conditions such as:

- Fetal Alcohol Syndrome (FAS), the most severe end of the FASD spectrum
- Partial FAS (PFAS)
- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Alcohol-Related Birth Defects (ARBD)
- Neurobehavioral Disorder associated with Prenatal Alcohol Exposure (ND-PAE)

Only about 10 percent of individuals with FASD display the facial abnormalities characteristic of FAS. Many children with FASD may look completely normal. While brain damage cannot be seen with the naked eye, the effects can be seen through the behaviors of the individual.

Key characteristics of a child with FASD include:

- Difficulty with assessment, judgment, impulse control, and reasoning which can result in trouble at home, at school, and with the law;
- Misunderstanding of causality and consequence which can lead to high rates of recidivism in the criminal justice system and problems with discipline;
- Inability to generalize or think abstractly which may result in an inability to apply lessons learned from one situation to another; and
- Trouble focusing and hyperactivity, poor memory, emotional immaturity and social skill deficits, and learning disabilities which may cause poor performance in school, trouble holding jobs, and difficulty managing at home.

Prenatal alcohol exposure is most detrimental when the nervous system is developing during the first trimester, often before many mothers know they are pregnant. It is safest not to drink at any time during pregnancy or while trying to become pregnant. While some myths may state otherwise, all types of alcohol are equally harmful to a developing baby.

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While there is not a cure for FASD, there are several protective factors that improve outcomes for individuals with an FASD.\textsuperscript{4} Stable, nurturing caregiving, early diagnosis and intervention, absence of violence, a stable home environment, and access to social and educational services have all been associated with improved functioning and independence. HHS is home to many programs and resources that support individuals and families in attaining these protective factors. Although these resources exist and can improve outcomes, preventing FASD from occurring is best.

**Focus Area: Preventing Disabilities Caused by Maternal Health Issues During Pregnancy**

ODPC also focuses on preventing disabilities caused by maternal health issues during pregnancy. A mother’s health before and during pregnancy has a big impact on how her baby develops neurologically and physiologically. A mother’s nutrition, exposure to toxins, or infections all have the potential to cause birth defects and permanent intellectual or developmental disabilities (IDD). As with preventing FASD, preconception care and prenatal care are crucial elements of both the mother and her baby’s health, and decrease the likelihood of a baby being born with a preventable disability. Proper preconception and prenatal care can help a mother maintain a healthy pregnancy, ultimately helping her baby’s development.

Preconception care can include discussing pregnancy plans or contraception use. While it might not seem like a woman’s health before becoming pregnant could make a big difference, it can have a tremendous impact on her future baby’s health and development. Preconception care can help prevent unplanned pregnancies and support a woman’s health as she tries to become pregnant and ultimately prevent a child from developing a disability before birth.

Prenatal care is the medical care a woman receives while she is pregnant. Prenatal care is for both the mother and baby, and greatly reduces the likelihood of premature birth, low birth weight, and birth defects. Both preconception care and prenatal care play a huge role in preventing some of the disabilities described below.

Neural tube defects (NTDs) are birth defects that affect the brain, spine, or spinal cord. The neural tube in a baby usually closes and develops into the brain and spinal cord by the end of the first month of pregnancy. If this development is not

completed, a baby is born with an NTD. Spina bifida and anencephaly are the two most common types of NTD.

Although most of the effects of NTDs cannot be reversed, up to 85 percent of NTDs can be prevented by the incorporation of folic acid into a mother’s diet.\(^5\) Since the neural tube develops so early during pregnancy, often before a woman knows she is pregnant, it is recommended that all women of childbearing age consume 400 micrograms of folic acid per day.\(^6\) Even with the consumption of enriched and fortified foods, it is very rare that a woman consumes enough folic acid every day through diet alone, so it is crucial for all women to also consume supplements or multivitamins that contain folic acid. Although many of the most popular daily multivitamins for women already include folic acid, a woman who would like to become pregnant should discuss when to start taking prenatal vitamins with their doctor before trying to conceive.

Premature birth and low birth weight can increase the risk of developmental disability for a child.\(^7\) Risk factors, such as prenatal tobacco or alcohol exposure, or maternal obesity, increase the risk of premature birth and low birth weight. Preparing for pregnancy with preconception care and early prenatal care can help prevent premature birth and low birth weight. Some treatments exist for women who have a higher risk of preterm labor, such as progesterone shots (17P).

Preexisting diabetes and obesity of the mother have been associated with higher rates of birth defects or premature birth which can result in developmental disabilities.\(^8\) It is important for women who would like to become pregnant or may become pregnant to work with their doctors to address and manage these chronic conditions.


\(^6\) Centers for Disease Control. Recommendations for the use of folic acid to reduce the number of cases of spina bifida and other neural tube defects. MMWR 1992;41(No. RR-14):(inclusive page numbers).


Certain medications, such as Accutane, can increase the likelihood of a child being born with birth defects. Prenatal exposure to certain medications can also increase the chances of low birth weight, premature birth, and developmental disabilities. A woman who is pregnant or planning to become pregnant should never stop taking medication without talking to her doctor.

Maternal infections can also affect a developing baby during pregnancy. Sexually transmitted infections, toxoplasmosis, chicken pox, and rubella are just a few of the infections that increase the risk of a baby being born with birth defects. Vaccinations, proper hygiene, and avoiding certain chores, such as cleaning the cat litter box, can protect mothers from some of these infections. Health care providers should be knowledgeable of the recommend vaccinations for pregnant women and discuss the possibility of infection during prenatal checkups.

**Focus Area: Preventing Acquired Brain Injury in Children**

In addition, ODPC focuses on preventing acquired brain injury in children. An acquired brain injury is brain damage caused by events after birth. Brain injuries are not related to genetic or congenital disorders, and differ from degenerative brain conditions, such as Alzheimer’s or Parkinson’s disease.

All types of brain injury are serious and can be life altering. Recovery often looks identical between different types of brain injury. Although there is no complete cure, many people recover and regain many of their abilities through therapy and treatment, or they adapt to and cope with their new limitations. The good news is that almost all brain injuries are preventable.

Traumatic brain injury (TBI) is a type of acquired brain injury. TBIs are caused by an external force that disrupts the normal function of the brain, such as a bump, blow, or jolt to the head or body, or a penetrating head injury. Common causes include:

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• Falls
• Being struck by/against something
• Motor vehicle crashes
• Assault

“Non-traumatic” brain injury, all other types of acquired brain injuries, are injuries caused by an internal event, rather than an external force. While this term is not a technical diagnosis, it helps differentiate between TBIs and other acquired brain injuries. Common causes include:

• Stroke
• Infections, such as meningitis or encephalitis
• No oxygen or too little oxygen making it to the brain from causes such as near drowning, asphyxiation, or aspiration
• Brain tumors
• Exposure to toxins in cleaning products, pesticides, lead, or mercury
• Drugs such as cocaine, methamphetamines, or opioids

The effects of a brain injury are different for every person. There is no way to determine how a brain injury will affect a person or how long those effects may last. The effects of a brain injury include:

• Cognitive effects, which include memory problems, difficulty concentrating, poor planning and judgment skills, language difficulties, and a lack of problem solving skills
• Sensory effects, such as altered visual/spatial perception, sense of touch and hearing, or vision impairments
• Emotional effects, including being impulsive, risky behavior, depression/anxiety, aggression, or paranoia
• Physical effects, including severe headaches, seizures, poor coordination and balance, slurred speech, and being unable to move

Focus Area: Promoting Early Identification and Diagnosis of Disabilities to Ensure Early Intervention and Services

To address disabilities that cannot be or are not prevented, ODPC promotes early identification and diagnosis of disabilities to ensure early intervention and services. Early intervention can make a difference in the lives of children who may have or have been diagnosed with a developmental disability. Connecting children with services early can build the foundation they need to develop their cognitive, behavioral, and physical skills as they grow. Early intervention can also dramatically reduce the cost of services later in a child’s life. However, early intervention is not possible without early identification. Families, medical providers, and other child-serving professionals have a role in tracking the development of a child to determine if they are falling behind.

While some disabilities may have more obvious physical or biological traits, others require the monitoring of behavior and skill development over time. The first five years of a child’s life are a crucial time for development, which is why these years are often when developmental disabilities are identified and diagnosed. Many tools exist to help parents, medical providers, child care professionals, educators, and other individuals track the developmental milestones of a child. Developmental milestones are things that a typically developing child should be doing at a certain age. Milestones can involve physical skills, coordination, social habits, communication, and speech. There are age ranges for most developmental milestones and each child will hit milestones at a different rate. If a child is late on a certain milestone, it may not be the result of a developmental disability but it is best to consult a child’s pediatrician.

12 See the ODPC website for a list of these resources: hhs.texas.gov/about-hhs/process-improvement/office-disability-prevention-children/early-identification-diagnosis. You can also visit cdc.gov/milestones to learn more about age specific milestones and find additional resources.
Focus Area: Promoting Mental Health Wellness for Individuals with an Intellectual or Developmental Disability

In addition, ODPC promotes mental health wellness for children with IDD. When a person has both a developmental disability and a mental health condition, it is called “co-occurring disorders” or sometimes called “dual diagnoses.” The co-occurrence of mental health conditions or substance use affects at least one-third of individuals with IDD. Unfortunately, there are many challenges facing children with co-occurring IDD and mental health conditions.

One major challenge is misinformation on this topic. Myths about whether or not a child with IDD can engage in behavioral health treatment or can experience a behavioral health issue prevent children from getting needed services. Research indicates children with IDD can experience mental illness, substance use disorders (SUD), and trauma just like their typically developing peers. Children with IDD also benefit greatly from behavioral health therapy and treatment. However, mental health providers do not always feel adequately trained to work with children with IDD and a shortage of mental health professionals exists in many communities in Texas.

Due to the myths, a lack of awareness, and a need for more professional development on the topic, many children are misdiagnosed or not diagnosed at all. If a child is diagnosed, the available resources for children with IDD are limited. ODPC understands more work is needed to address this issue to ensure children with IDD experiencing mental illness or SUD, or have experienced trauma, get the services and supports they need.

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4. HHS and DFPS Activities Impacting Disability Prevention

As ODPC began hosting stakeholder meetings and conversations, it became apparent there was not an existing catalogue of the programs and projects within the HHS System, inclusive of both HHSC and the Department of State Health Services (DSHS), and DFPS that impact disability prevention for children. ODPC therefore met individually with internal programs, hosted stakeholder meetings, and established or participated in related workgroups to learn more about disability prevention efforts taking place across the System. This review of other programs and efforts in place will help prevent duplicative efforts, encourage collaboration, and improve the outcomes of disability prevention projects in Texas. The following is a summary of the programs and projects within HHS and DFPS that impact disability prevention in each of the five ODPC focus areas.

Focus Area: Preventing Disabilities Caused by Prenatal Alcohol or Substance Exposure

Health and Human Services

An important part of FASD prevention is maternal health care. Family planning, preconception care, and prenatal care all offer ways for health care providers to improve birth outcomes and overall health. In the case of preventing an FASD, a woman should discontinue alcohol consumption before attempting to get pregnant and continue to abstain from drinking throughout the entire pregnancy. However, this is complicated by the high rate of unintended pregnancies in the U.S., estimated at almost half of all pregnancies.14 Even when pregnancies are planned, most women do not find out they are pregnant until four to six weeks into the pregnancy.15


Women’s health programs such as **Healthy Texas Women** and the **Family Planning Program** help prevent prenatal alcohol exposure by preventing unintended pregnancies and promoting family planning and preconception care.

Ensuring women have access to correct and helpful information about prenatal alcohol exposure is crucial. The **Texas Health Steps (THSteps) Online Provider Education (OPE)** platform offers over 50 free courses with continuing education units for a variety of health care professionals. The course on FASD, **FASD: Promoting Early Identification and Support for Children**, provides health care providers with the latest information on FASD and effective strategies to share this information with patients.\(^{16}\) **Texas Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)** is another program that educates parents on the risks of prenatal alcohol exposure. In addition to courses and information on nutrition, breastfeeding, and preparing for the baby, WIC clinics provide information on FASD.

Women should receive information on the risks of prenatal substance exposure and stop all substance use before becoming pregnant. However, when this does not occur, there is still the opportunity to educate a pregnant mother at prenatal visits. Not only does prenatal care give providers the opportunity to educate patients, it also is a time to assess for substance use and refer to treatment. While the benefits and eligibility requirements are not all the same, there are several HHS programs that provide pregnant mothers with prenatal care, including **Medicaid, Children’s Health Insurance Program (CHIP)** and **Title V Maternal and Child Health (MCH) Fee-for-Service Program**.

Medicaid provides reimbursement for **Screening, Brief Intervention, and Referral to Treatment (SBIRT)**. SBIRT is a comprehensive, public health approach to the delivery of early intervention and treatment services for clients with SUD, as well as those who are at risk of developing SUD, when provided to clients who are 10 years of age or older. Obstetricians can bill SBIRT separate and apart from the prenatal care visit. This practice aligns with recent American College of Obstetricians and Gynecologists guidance calling for routine SUD screening for all pregnant women.

A comprehensive SUD treatment benefit is available in the Medicaid for Pregnant Women coverage package, including assessment, individual and group SUD counseling, residential treatment, residential and ambulatory detoxification, and medication assisted treatment. CHIP Perinatal does not cover SUD treatment during pregnancy.

Programs such as Substance Abuse Prevention services at HHSC target subgroups that are determined to be at risk for substance abuse. Funded intervention and treatment programs address health concerns and risks associated with substance-abusing behaviors to the eligible population and provide direct education to pregnant women regarding health risks. In Texas, there is an array of services that can support a woman as she seeks recovery. Substance use services for adolescents and adults include detoxification services, residential and outpatient services, specialized female services, case management, and more. Pregnant women who need treatment for substance use, regardless of ability to pay, can receive immediate help in Texas.

**Department of Family and Protective Services Programs**

Within DFPS, several of the Prevention and Early Intervention (PEI) programs provide education and support to pregnant women and families. Home visiting programs support at-risk pregnant mothers and parents of young children through parenting education and basic needs support through community partners. Programs like Nurse Family Partnership and Parents as Teachers connect with parents during pregnancy and have the opportunity to provide education to improve pregnancy outcomes, including preventing prenatal alcohol exposure.

**Focus Area: Preventing Disabilities Caused by Maternal Health Issues During Pregnancy**

Many of the programs that impact the prevention of prenatal substance exposure also impact preventing other disabilities that result from maternal health issues or behaviors during pregnancy.

**Health and Human Services**

Just as prenatal care is important to the health of a mother and child, preconception care helps maximize health outcomes. Preconception care helps a woman prepare for pregnancy by eliminating certain behaviors such as alcohol or drug use, or by taking on new habits such as taking prenatal vitamins. Programs such as Healthy Texas Women or the Family Planning Program, have a
positive impact on preventing disabilities caused by maternal health issues by preventing unintended pregnancies and promoting family planning and preconception care. In addition, Healthy Texas Women also provides basic coverage for the screening and treatment of certain chronic health conditions such as diabetes, which can increase the risk of a child having a developmental disability if they are not managed.

For women who qualify, Medicaid and CHIP provide preconception care, and Medicaid, CHIP, and CHIP Perinatal provide pregnant mothers with prenatal care, including immunizations, in addition to education and guidance on pregnancy. Medicaid, CHIP, and CHIP Perinatal also cover 17P, an injection for pregnant women that provides extra progesterone to prevent preterm birth. Title V Maternal and Child Health Fee for Service Program also offers prenatal care services to pregnant women for up to 60 days while they are applying for CHIP Perinatal or Medicaid.

Although these services exist, not all women seek prenatal care as early as recommended. A pilot program, Healthy Families, was established to address this issue and is exploring ways to enhance early entry and engagement into prenatal care in Hidalgo and Smith counties.

OPE offers free courses and continuing education units on a variety of topics including prenatal and preconception care to ensure providers stay current on best practices. OPE has two modules on preconception and prenatal health. These modules, Preconception Health: Screening and Intervention and Prenatal Health: Screening and Intervention, include information on managing chronic health issues before and during pregnancy, identifying and intervening in high-risk behaviors, cytomegalovirus, and the importance of maintaining oral health during pregnancy.

Nutrition is an important component of a woman’s health during pregnancy and while breastfeeding. Babies need key nutrients like iron and folic acid for development during pregnancy and after birth. Texas WIC is a nutrition program for pregnant women, breastfeeding women, and families with children younger than five. Through Texas WIC, women and families receive education and supplemental foods to help support the nutritional needs of a developing baby.

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17 Kormondy, M. and Archer, N. 2017 Healthy Texas Babies Data Book. Austin, TX: Division for Community Health Improvement, Texas Department of State Health Services, 2017.

18 Available at https://www.txhealthsteps.com./165-preconception-and-prenatal- health-overview
The DSHS Immunization Unit works to eliminate the spread of vaccine-preventable diseases, increase vaccine coverage, raise awareness of diseases that vaccines prevent, and educate the public about vaccine safety. The Immunization Unit prevents the spread of diseases through programs like the Adult Safety Net program, provider and public education campaigns, and immunization tracking. Some of the diseases prevented can result in a developmental disability for a child if contracted by the mother during pregnancy. Additionally, the immunization program operates the Texas Perinatal Hepatitis B Prevention Program, which works alongside public and private health care providers and coalitions to prevent perinatal hepatitis B transmission.

**Department of Family and Protective Services Programs**

PEI programs aid in preventing maternal health issues which may result in a developmental disability. PEI programs provide education and support to pregnant women and families to improve the health outcomes of both the mother and child. Programs like Nurse Family Partnership and Parents as Teachers connect these families to a health care professional that can answer many of their pregnancy-related questions. Meeting with families throughout pregnancy, home visiting staff have the opportunity to educate families on how to have a healthy pregnancy and start a family.

**Focus Area: Preventing Acquired Brain Injury in Children**

**Health and Human Services**

The Office of Acquired Brain Injury (OABI) is the center for awareness and education on brain injuries in Texas. OABI educates on, raises awareness of, and encourages the prevention of acquired brain injury. OABI has a collection of educational videos and materials on various brain injury-related topics. In collaboration with its partners, OABI hosts conferences, attends events, connects people to resources and services, and trains people on brain injury in an effort to raise awareness and educate on prevention strategies. The OPE module Concussion: Diagnosis, Treatment, and Prevention equips THSteps providers and others to identify, treat, and reduce the risk of concussions in children and adolescents. While preventing all concussions is not possible, a provider that can
diagnose and provide recovery guidance can reduce the risk of further injury.\(^1\) Related OPE content around preventing brain injury includes modules \textit{Preventing Unintentional Injury} and \textit{Recognizing, Reporting, and Preventing Child Abuse}.\(^2\)

As motor vehicle crashes are a leading cause of TBI, encouraging the correct use of seat belts and child safety seats is an important part of brain injury prevention. The \textbf{DSHS Safe Riders Traffic Safety Program}'s goal is to reduce motor vehicle crash-related injuries and fatalities. Through education and child safety seat distribution, this program has a positive impact on reducing brain injuries during motor vehicle crashes. In addition to this program, \textbf{Medicaid} managed care organizations (MCOs) may offer value-added services to their members, which can include child safety seats as well as bicycle helmets.

Although less common, some brain injuries are caused by infections. While the goal of the \textbf{DSHS Immunization Unit} is not to prevent brain injury, the prevention of the spread of vaccine-preventable diseases includes some diseases that can lead to infections that cause brain injury. Vaccine-preventable diseases like meningitis, measles, and chicken pox can cause swelling in the brain and lead to brain damage. Not every case will result in brain injury, but it is crucial to encourage the prevention of these diseases for this and other health-related reasons. Children in \textbf{Medicaid} and \textbf{CHIP} are able to receive immunizations based on a periodicity schedule ensuring that children have access to needed vaccinations. The \textbf{OPE} website also offers an online provider education course on immunizations.\(^3\) The \textit{Immunization} module equips health care professionals to apply for national immunization schedules and recommendations, counsel parents about immunizations, and employ best practices for vaccine administration, storage and handling, and reporting.

\textbf{Department of Family and Protective Services Programs}

Falls and assault are both leading causes of brain injury for all ages, especially in children. \textbf{PEI} programs address both of these causes through \textit{Home Visiting}

\(^1\) Available at \url{https://www.txhealthsteps.com/388-concussion-diagnosis-treatment-and-prevention}.


\(^3\) Available at \url{https://www.txhealthsteps.com/146-immunization}. 

Programs and the Help and Hope website. Home visiting programs prevent child abuse by educating and supporting parents as they figure out what parenthood is like. The Safe Babies Project evaluates hospital and clinic-based interventions designed to prevent maltreatment, especially abusive head trauma, in the first year after birth. Part of this evaluation incorporates programming, such as the Period of PURPLE Crying, that prevents shaken baby syndrome and abusive head trauma. The four phases of this project aim to provide an evidence base for scalable parental education that supports positive parenting and provides tools to help both parents cope with the difficult aspects of caring for an infant. Help and Hope provides parenting guidance and advice for children of every age, as well as home safety tips to reduce falls. While rare, near drowning can be a cause of brain injury. An entire section of the Help and Hope website is dedicated to water safety to help parents be the best water guardians they can be. Parents can go to Help and Hope to read, watch videos, or download materials to help them with parenting challenges and ensure their child is safe at home and in their community.

Focus Area: Promoting Early Identification and Diagnosis of Disabilities to Ensure Early Intervention and Services

Health and Human Services

Parents, childcare staff, medical professionals, and other child-serving professionals have a role in early identification and diagnosis of developmental disabilities. The education of these groups and accessible resources increase the likelihood of early identification of disabilities. As a provider of early intervention services, Early Childhood Intervention (ECI) encourages families to monitor their child’s development and seek out professional judgement when there is a concern. In addition to providing information on where to find professionals in local communities, the program provides information on what families should be looking for and other available resources in Texas. ECI providers support childcare facilities and other local organizations to screen children for developmental delays. Referrals to other programs are an integral part of the WIC Program. Dietitians and

22 Available at www.HealthandHope.org

23 An evidence-based shaken baby syndrome/abusive head trauma prevention program by helping parents and caregivers understand the frustrating features of crying in normal, healthy infants that can lead to shaking or abuse.
nutritionists assess and counsel families on key nutrition needs at each developmental stage, which may include a referral to ECI services.

The **Navigate Life Texas** website is a statewide resource containing information on tracking development and how to respond to concerns through the eyes of a parent. The website has information and videos on developmental milestones, what to do if there are concerns and what to talk to a child’s doctor about.\(^{24}\) Parents write subject-specific blogs providing experience and tips.\(^{25}\) The information on Navigate Life Texas is written in both English and Spanish and is easy to understand. The website also contains information on services and resources for children with IDD in Texas.

Health care providers can access free accredited online training on how to perform developmental screenings during office visits and many other courses through the **OPE** website.\(^{26}\) All training content on the website is free, self-paced, and developed by leading experts, including the course *Developmental Surveillance and Screening: Birth through 6 Years* and *Autism Spectrum Disorder: Screening, Diagnosis, and Treatment*.

DSHS **MCH** received a federal grant: Project Linking Action for Unmet Needs in Children’s Health (LAUNCH). The grant is designed to improve children’s social and emotional development from ages birth through 8. In partnership with Aliviane Inc. and the Texas Institute for Excellence in Mental Health at The University of Texas, MCH has been increasing and improving developmental screening and assessment in a range of child-serving settings. Starting in 2015, the four-year **Texas LAUNCH** project has been implemented in three communities: Ysleta del Sur Pueblo in El Paso, My Health My Resources of Tarrant County in Fort Worth, and Family Services Association of San Antonio. Texas LAUNCH local communities provide trainings and technical assistance on the Ages and Stages Questionnaire (ASQ) developmental screening tools, develop referral protocols for positive screenings, and increase the number of children receiving developmental screenings. Texas LAUNCH is also


expanding services statewide to train childcare providers, childcare health consultants, Head Start, United Way, and ECI providers on how to be an ASQ Trainer of Trainers to train other staff on the ASQ tools to expand the use of developmental screenings for children in organizations they serve.

**Medicaid and CHIP** MCOs are required to develop and maintain a system and procedures for identifying Members with Special Health Care Needs (MSHCN). The MCO must have effective systems to ensure the provision of covered services to meet the special preventive, primary acute care, and specialty health care needs appropriate for treatment of the members with special health care needs conditions. The MCO must provide service management to MSHCN, including the development of a service plan and ensuring access to treatment by a multidisciplinary team when necessary.

The DSHS **Newborn Screening (NBS) Clinical Care Coordination Program** seeks to decrease the morbidity and mortality of infants born in Texas through customer-oriented, high quality newborn screening follow-up, case management, and outreach education. All newborns in Texas receive 2 screens for 53 genetic conditions identifiable by dried blood spots, plus 2 point-of-service screens for a total of 55 newborn screenings. An abnormal laboratory result triggers follow-up and case management to ensure the baby receives confirmatory testing and treatment, if needed. Early treatment can prevent serious complications including developmental delays and intellectual disability. While the conditions themselves screened through this program are not preventable, early identification is crucial as some of these conditions, such as congenital hypothyroidism, can result in a developmental disability if not treated. The OPE website features a training on newborn screening.²⁷ This module equips health care professionals to actively engage in the state’s newborn screening program, correctly interpret and act upon results, educate parents, and provide appropriate follow-up and referral when necessary.

The DSHS **Texas Early Hearing Detection and Intervention (TEHDI)** is part of NBS in Texas. Without early identification and intervention, children who are deaf or hard of hearing may experience delays in vocabulary, communication, and cognitive skills development. TEHDI is dedicated to ensuring that newborns and young children who are deaf or hard of hearing are identified as early as possible. TEHDI certifies and renews newborn hearing screening, tracking, and intervention

programs in Texas and is instrumental in supporting providers in performing screenings and ensuring appropriate referral to services.

**Department of Family and Protective Services Programs**

PEI **Home Visiting** programs offer developmental assessments which may indicate a delay. If a delay is identified, the Home Visitor will talk with the family, create a referral, and assist the family with finding the appropriate services.

**Focus Area: Promoting Mental Health Wellness for Individuals with an Intellectual or Developmental Disability**

**Health and Human Services**

HHSC is committed to promoting mental health wellness for individuals with IDD. The **Texas Statewide Behavioral Health Strategic Plan** identifies gaps in services in hope of strengthening behavioral health services provided in Texas. The vision of this strategic plan is to ensure that Texas has a unified approach to the delivery of behavioral health services that allows all Texans to have access to care at the right time and place. Gap 9 of the strategic plan highlights the need for improvements in behavioral health services for individuals with IDD. With the support of various state agencies, this strategic plan guides behavioral health efforts in Texas.

Individuals with IDD who are enrolled in **Medicaid** have access to the full array of Medicaid benefits, including behavioral health services and any waiver services for which they may qualify, such as behavior support services.

HHSC created a training that equips direct service workers with the knowledge and skill needed to best support an individual with IDD who may be experiencing mental illness. This free online training, **Mental Health Wellness for Individuals with IDD**, is now a requirement for staff at many organizations that work with individuals with IDD. The training is maintained by HHSC and is currently being expanded to include additional modules for clinical professionals.

For many parents, understanding their child’s benefits and knowing where they can find mental health services and resources is a challenge. **Navigate Life Texas**
contains information on co-occurring IDD and mental health concerns. The website also connects families with support groups, services and events that may help parents. 

**OPE courses** *Behavioral Health: Screening and Intervention, Childhood and Adolescent Depression* and *Experiences through Trauma-Informed Care* train providers on screening children for behavioral health needs and providing trauma-informed care.

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29 Available at https://www.navigatelifetexas.org/en/services-groups-events.

5. ODPC’s Fiscal Year 2018 Efforts

Focus Area: Preventing Disabilities Caused by Prenatal Alcohol or Substance Exposure

Activities

In fiscal year 2018, ODPC focused on preventing prenatal alcohol and substance exposure through education and raising awareness. On October 5, 2017, ODPC presented at the Partners in Prevention Conference in San Antonio. The session focused on understanding and addressing stigma around prenatal substance use and was attended by home visiting program staff, child protective services staff, and others.

Additionally, after reviewing the client education materials available through HHS, ODPC began working on a new educational flyer on FASD. This new FASD flyer includes up-to-date and Texas-specific information on prenatal alcohol exposure. The flyer is featured on the ODPC website and will soon be available through other programs such as WIC, THSteps, and Healthy Texas Women. The flyer educates readers on the risk of prenatal alcohol exposure and provides resources for both parents and children.

To address the training needs of providers, ODPC worked with the THSteps team to produce a quick course on FASD. Quick courses do not provide continuing education units but can be completed in about fifteen minutes, giving providers the opportunity to review information on a certain topic. The FASD course was completed in August 2018 and contains information on the prevention of, identification and diagnosis of, and referral to services for FASDs. The course


connects providers with further information and resources to strengthen their knowledge of FASD.

**Ongoing Strategies**

ODPC will continue to seek speaking opportunities to educate parents and professionals on the risks of prenatal alcohol exposure. ODPC will seek opportunities to partner with other HHS programs, such as THSteps and WIC, to develop trainings for both families and professionals. Maintaining the ODPC website information on prenatal substance exposure will also remain a priority for ODPC. To raise awareness, ODPC will feature social media posts and website articles on the risks of prenatal substance exposure during FASD awareness month in September and throughout the year.

**Focus Area: Preventing Disabilities Caused by Maternal Health Issues During Pregnancy**

**Activities**

Through the Better Birth Outcomes (BBO) initiative, ODPC partners on projects throughout the HHS system that focus on improving birth outcomes. A number of these programs indirectly prevent developmental disabilities by improving the health of the mother during pregnancy. ODPC aims to amplify the results of these programs by supporting their work.

**Ongoing Strategies**

ODPC would like to support existing programs by educating program clients or providers on the various ways that a mother’s health during pregnancy could affect her baby’s chance of having a developmental disability. ODPC will continue to collaborate with BBO partners and other groups related to maternal health issues.

**Focus Area: Preventing Acquired Brain Injury in Children**

**Activities**

ODPC focused on education to prevent brain injury in fiscal year 2018. In the spring of 2018, ODPC worked with THSteps to develop a module on concussion. The *Concussion: Diagnosis, Treatment, and Prevention* training is now available for free
on the THSteps website. Participants learn how to identify, treat, and reduce the risk of concussions in children and adolescents. In addition, in August 2018, ODPC presented at the South Texas Adolescent Health Summit on concussion management for teens.

ODPC worked with OABI and the Comprehensive Rehabilitation Services (CRS) program to create a Texas Brain Injury Resource Guide. The resource guide provides information on resources for individuals with a brain injury. The Texas Brain Injury Advisory Council (TBIAC) provided service recipient and professional review of the resource guide.

In March, ODPC, OABI, and CRS led Texans in a statewide campaign to raise awareness of brain injury through the 2018 Brain Injury Awareness Month (BIAM) Campaign. The programs partnered with Hope After Brain Injury, Brain Injury Alliance, and Team Luke Hope 4 Minds to expand the reach of the campaign and incorporate stakeholder input in the planning and execution of activities. On March 6, ODPC co-hosted a BIAM celebration in Austin. The celebration included a resource fair, an art exhibit, and testimonials from individuals with a brain injury and professionals. The event was attended by over 80 brain injury professionals, individuals with a brain injury, family members, and HHS employees. On March 23, ODPC helped host a free training, Serving and Supporting Individuals with a Brain Injury, in Austin and via webinar. Attendees learned the basics of brain injury, gained an understanding of the challenges faced by individuals with a brain injury, and learned how to best help them find the services and supports they need. The 138 attendees included social workers, school nurses, parents, and HHS employees. The training was approved for continuing education units for the Guardianship program, and the recording will be adapted to be offered to Guardianship staff on the program’s online training system.

ODPC also developed a BIAM calendar which included events from around the state, as well as information on how to get involved in BIAM activities. Throughout March, emails were sent out to over 68,000 individuals to provide information on the events and BIAM campaign. HHS featured articles on the employee intranet and the HHS homepage about the March campaign and the three programs leading it. Navigate Life Texas supported the campaign with a banner on its homepage that directed parents to information about BIAM activities. Weekly posts on the HHS Facebook and Twitter pages included information on prevention, brain injury

identification and resources. These posts reached over 125,000 people on Facebook and over 2,000 on Twitter.

**Ongoing Strategies**

ODPC will continue to seek opportunities to present to or train families and professionals on preventing brain injury in children. Following the success of the BIAM Campaign in 2018, HHS plans to make this a yearly activity led by ODPC, OABI, and CRS. ODPC will maintain the brain injury information on its website and will assist with keeping the Texas Brain Injury Resource Guide up to date. Moving forward, ODPC would like to create client materials about preventing brain injury in children. Where appropriate, ODPC will support programs in implementing policies that encourage brain injury prevention.

**Focus Area: Promoting Early Identification and Diagnosis of Disabilities to Ensure Early Intervention and Services**

**Activities**

ODPC participates in the quarterly Texas LAUNCH meetings at which local teams and various agency representatives come together to discuss increasing early childhood developmental screening and assessment in Texas. ODPC also participates on Texas LAUNCH Developmental Screening Workgroup which promotes children receiving developmental screenings. In addition to supporting Texas LAUNCH, ODPC promotes ECI through the ODPC website, during speaking engagements, and in printed materials. ODPC has also ensured there is ECI representation at its stakeholder and workgroup meetings.

**Ongoing Strategies**

With many existing successful projects and initiatives, ODPC will play a supporting role and help facilitate collaboration on early identification and diagnosis of disabilities. As ODPC continues to grow, supporting ECI and Texas LAUNCH will remain a priority. ODPC will promote training and continuing education on developmental screening and early identification. ODPC will continue to seek opportunities to improve early identification within HHS and DFPS.
Focus Area: Promoting Mental Health Wellness for Individuals with an Intellectual or Developmental Disability

Activities

The lack of awareness of co-occurring IDD and mental health conditions remains a key challenge in promoting mental health wellness for individuals with IDD. To address this challenge, ODPC’s efforts include awareness-raising and educational activities to bring the subject to the attention of both families and professionals.

On May 4, ODPC co-hosted the first Co-Occurring Intellectual and Developmental Disability and Mental Health Conditions Collaboration meeting. The meeting was attended by 170 people in person and online. From this meeting, ODPC and its partners were able to establish a vision for the future of this group and will continue to host periodic stakeholder meetings on this topic to discuss best practices and opportunities for collaboration. In addition to this stakeholder group, ODPC participates in another cross-agency workgroup that meets monthly to discuss how each agency is addressing the mental health needs of children and adults with IDD.

Beginning in May 2018, ODPC partnered with SAFE, a merger of Austin Children’s Shelter and SafePlace in Austin/Travis County, to provide a free training called The Road to Recovery: Supporting Children with Intellectual and Developmental Disabilities Who Have Experienced Trauma. This two-day train-the-trainer teaches basic knowledge, skills, and values related to working with children with IDD who have had traumatic experiences. Trainings were held on May 8 through 9, June 25 through 26, July 16 through 17, and July 31 through August 1. Over 150 people attended these trainings including educators, medical professionals, mental health professionals, HHS staff, and others.

On August 29, ODPC presented on Mental Health and Teens with Intellectual and Developmental Disabilities at the South Texas Adolescent Health Summit in Edinberg, Texas. The session provided information on the increased risk of mental health concerns for individuals with IDD, signs and symptoms of mental health issues in adolescents with IDD, and community supports and resources.

Ongoing Strategies

Moving forward, ODPC will continue to work with its partners to seek out resources, best practices, and available educational opportunities regarding co-occurring IDD
and mental health conditions, and hopes to continue to support the *Road to Recovery* trainings. Attending and participating in workgroup meetings will ensure ODPC is knowledgeable about what services exist for children with IDD who experience mental health concerns and how these services might interact. Continuing to raise awareness through speaking engagements will be a priority for ODPC.
6. Conclusion

ODPC accomplished many things during fiscal year 2018. With its partners, ODPC created new training for health care providers, educational materials for HHS clients, and resource guides for families. ODPC raised awareness of brain injury, FASD, and co-occurring IDD and mental health conditions through events, speaking engagements, and social media campaigns. The program will continue partnerships with other state agencies and stakeholders to accomplish its goals and promote disability prevention for children.

ODPC has created a catalog of the programs and projects within the HHS System and DFPS that impact disability prevention in children. This review of existing programs will increase awareness of what the State of Texas is doing in regards to disability prevention, prevent duplicative efforts, and increase collaboration across programs. ODPC will continue to meet with programs and participate on related workgroups to keep a current knowledge of activities that have the potential to prevent disabilities.

Stakeholders will continue to play a critical role in guiding ODPC’s work. ODPC will continue to host stakeholder meetings to share and receive feedback. In addition, ODPC will continue to participate on workgroups and attend meetings related to the areas of focus. Through collaboration, ODPC plans to continue to seek ways to prevent disabilities in children throughout Texas.
## List of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
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<tbody>
<tr>
<td>ARBD</td>
<td>Alcohol-Related Birth Defects</td>
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<tr>
<td>ARND</td>
<td>Alcohol-Related Neurodevelopmental Disorder</td>
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<td>BBO</td>
<td>Better Birth Outcomes</td>
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<td>BIAM</td>
<td>Brain Injury Awareness Month</td>
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<td>CHIP</td>
<td>Children's Health Insurance Program</td>
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<td>DFPS</td>
<td>Department of Family and Protective Services</td>
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<td>DSHS</td>
<td>Department of State Health Services</td>
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<tr>
<td>ECI</td>
<td>Early Childhood Intervention</td>
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<td>FAS</td>
<td>Fetal Alcohol Syndrome</td>
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<tr>
<td>FASD</td>
<td>Fetal Alcohol Spectrum Disorders</td>
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<td>HHS</td>
<td>Health and Human Services</td>
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<td>HHSC</td>
<td>Health and Human Services Commission</td>
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<tr>
<td>IDD</td>
<td>Intellectual and developmental disabilities</td>
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<tr>
<td>LAUNCH</td>
<td>Linking Actions for Unmet Needs in Children’s Health</td>
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<tr>
<td>NBS</td>
<td>Newborn Screening Program</td>
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<tr>
<td>ND-PAE</td>
<td>Neurobehavioral Disorder associated with Prenatal Alcohol Exposure</td>
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<td>NTD</td>
<td>Neural Tube Disorder</td>
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<tr>
<td>OABI</td>
<td>Office of Acquired Brain Injury</td>
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<td>Acronym</td>
<td>Definition</td>
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<tr>
<td>ODPC</td>
<td>Office of Disability Prevention for Children</td>
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<td>OPE</td>
<td>Online Provider Education</td>
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<td>PEI</td>
<td>Prevention and Early Intervention</td>
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<td>PFAS</td>
<td>Partial Fetal Alcohol Syndrome</td>
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<tr>
<td>TBI</td>
<td>Traumatic Brain Injury</td>
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<tr>
<td>TEHDI</td>
<td>Texas Early Hearing Detection and Intervention</td>
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<tr>
<td>TIEMH</td>
<td>Texas Institute for Excellence in Mental Health</td>
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<tr>
<td>TOPDD</td>
<td>Texas Office for the Prevention of Developmental Disabilities</td>
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<tr>
<td>WIC</td>
<td>Women, Infants and Children</td>
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