

How is the Division of Health Improvement working to prevent abuse of individuals with intellectual and developmental

disabilities? Individuals with intellectual and developmental disabilities (I/DD) are a diverse group of people with different vulnerabilities. Cognitive challenges, dependence on the care provided by other people, difficulty communicating needs, challenging behaviors and poor memory or recall are some of the factors that contribute to the increased vulnerability of people with I/DD. Many adults with I/DD are unable to recognize danger, understand rights and protect themselves against actions or inactions that are illegal, abusive or in any way threatening to their health and emotional, financial and physical well-being. Historically, people with I/DD have been discriminated against because of their disabilities, separated from society-at-large and denied opportunities for education and other life experiences.

Misperceptions and stereotypes about people with disabilities also put people with I/DD at an increased risk to experience abuse and neglect. Many people with I/DD have limited social contacts and activities and experience negative attitudes from other people, or social stigma. They are often not believed or listened to by immediate contacts and not seen as credible with law enforcement or in court. In addition, the desire to please people in authority positions or peers and the desire to be included

may influence these individuals' decision-making. In other cases, they are not aware that what is occurring is abusive, do not want to end a relationship that is unhealthy, or fear the change in living arrangements.

<u>Trends</u>

Since 2009, the United States' rate of violent victimization - including rape/sexual assault, robbery, and aggravated assault - has increased almost 25% among individuals with disabilities, from about 29 per 1,000 people with disabilities to 36 per 1,000. Comparatively, the rate of violent

In SFY2018

955 investigations of abuse, neglect or exploitation were conducted.

265 allegations of abuse, neglect or exploitation were substantiated.

194 consumers were determined to have been the victim of abuse, neglect or exploitation.

victimization among individuals without disabilities has increased by less than 1%. In 2013, the rate of violent victimization among individuals with disabilities was more than **two times** that of individuals without disabilities.¹

The Incident Management Bureau (IMB) serves individuals with I/DD by assessing needs and providing protective services in community-based programs through investigations of allegations of abuse, neglect and exploitation, often collectively referred to as "abuse" or ANE. New Mexico state law requires all persons with knowledge about potential ANE to report; this includes people who work directly with individuals with I/DD. All family, friends and people who provide support can report abuse. Reports also come from law enforcement, medical providers and other sources. IMB maintains a 24-hour ANE reporting hotline.

- An IMB Intake Specialist gathers preliminary information to assess the need for protection of the vulnerable adult and determine if a situation meets the definition of abuse (ANE). An adult is considered anyone over 18 years of age. The Intake Specialist provides notification to certain individuals and entities, including the individual's case manager. The Community-Based Provider is responsible for delivery of an immediate action and safety plan (IASP) to the DHI Hotline and is required to update the IASP if instructed to by the assigned Investigator.²
- Once it is determined that an allegation meets the definition of abuse, neglect or exploitation, as defined by the New Mexico Administrative Code (NMAC), the case is screened in and an Investigator is assigned. The case is assigned a Priority Level, depending on the seriousness of the allegation. An Emergency requires the Investigator respond within three hours, a Priority One requires a 24-hour response and a Priority Two requires the Investigator respond within five days.

¹ Bureau of Justice Statistics, Crime Against Person with Disabilties, 2009 - 2013 Statistical Tables, (U.S. Department of Justice, 2015), https://www.bjs.gov/content/pub/pdf/cap0913st.pdf.

² If the person is under 18 years of age, the report is forwarded to the Children, Youth and Families Department (CYFD).

- The Investigator will begin an investigation into the nature and cause of the abuse. The Immediate Action and Safety Plan (IASP) is continually assessed to ensure the health and safety of the alleged victim while the investigation progresses. Examples of actions that can be taken in an IASP can be found below.
- The Investigator also makes a mandatory report to law enforcement if they believe a crime has been committed.
- When an investigation is complete, the investigator determines a finding: either Substantiated or Unsubstantiated based on a preponderance of the evidence.
- Next, the Investigator determines what corrective/preventive actions will be taken to ensure the individual remains safe. These corrective/preventive actions are individually tailored to each situation, whether abuse has been determined to have occurred or not. The purpose of corrective/preventive actions is to mitigate risk, increase safety, and provide education and training, based on deficient practice. Examples of corrective/preventive actions could include: retraining on healthcare plans, mandatory abuse reporting training for all program staff, updating the persons Individual Service Plan, re-evaluating the need for increased supervision or disciplinary action for the Agency employee, including termination of employment, for serious violations.

In SFY18 law enforcement agencies were most likely to get involved in sexual, financial and physical abuse allegations. Exploitation cases were most likely to be successfully prosecuted. A law enforcement agency is notified any time there is reasonable cause to believe a crime has been committed.

As part of our ongoing effort to work more closely with law enforcement agencies around the state, in FY2017 IMB conducted training with over a dozen law enforcement agencies throughout New Mexico, to educate them about the Incident Management Bureau, what we do, and how to work more effectively with people with Intellectual and Developmental Disabilities.

IMB also provided outreach to about 3,000 physicians in the state, to educate them on how to recognize the signs and symptoms of abuse, neglect and exploitation, and where to report their concerns.

Who do we serve?

DHI and its partners provide supports and services to adults who meet eligibility criteria for the Medicaid Developmental Disabilities (DD) Waiver, Mi Via Self-Directed Waiver and the Medically Fragile³ Waiver programs. Intellectual disability is characterized by limitations both in intellectual functioning (reasoning, problem solving) and in adaptive behavior, which covers a wide range of everyday social and practical skills. The disability originates before the age of 18. "Developmental Disabilities" is an umbrella term that includes intellectual disability but also includes other disabilities that are apparent before the age of 22 and are likely lifelong. Some developmental disabilities are largely physical issues, such as cerebral palsy or epilepsy. Some individuals may have a condition that includes physical and intellectual disability, for example Down syndrome. Some people with developmental disabilities also have significant medical or mental health needs. In SFY2018, the number of adults enrolled in I/DD services through the DD Waiver, Mi Via Self-Directed Waiver and the Medically Fragile Waiver programs continues at about 4,632.

Mission Statement

IMB exists to ensure the health, safety, and well-being of individuals served on the DD Waiver, the Mi Via Self-Directed Waiver and adults on the Medically Fragile Waiver, by investigating allegations of abuse, neglect, exploitation, suspicious injury, environmental hazard, and death.

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³ For the Medically Fragile waiver, IMB only has authority to investigate cases involving adults. Any allegation involving a child on the waiver is referred the Children, Youth and Families Department.

What is Abuse, Neglect or Exploitation?

Abuse is defined as:

- (1) knowingly, intentionally, and without justifiable cause inflicting physical pain, injury or mental anguish;
- (2) the intentional deprivation by a caretaker or other person of services necessary to maintain the mental and physical health of a person; or
- (3) sexual abuse, including criminal sexual contact, incest and criminal sexual penetration. New Mexico Administrative Code 7.1.14.7(A).

Abuse can be physical (as described above): inflicting pain, injury, and/or mental anguish. It can also be sexual or verbal.

Sexual Abuse is defined as the inappropriate touching of a recipient of care or services for sexual purpose or in a sexual manner, and includes kissing, touching the genitals, buttocks, or breasts, causing the recipient of care or services to touch another for sexual purpose, or promoting or observing for sexual purpose any activity or performance involving play, photography, filming, or depiction of acts considered pornographic. Sexual conduct engaged in by an employee with a person for whom they are providing care or services is sexual abuse per se. NMAC 7.1.14.7(AA).

Verbal Abuse is defined as profane, threatening, derogatory, or demeaning language, spoken or conveyed with the intent to cause mental anguish. NMAC 7.1.14.7(EE).

Mental Anguish is defined as a relatively high degree of mental pain and distress that is more than mere disappointment, anger, resentment, or embarrassment, although it may include all of these, and is objectively manifested by the recipient of care or services by significant behavioral or emotional changes or physical symptoms. NMAC 7.1.14.7(Q).

Neglect is defined as the failure of the caretaker to provide basic needs of a person, such as clothing, food, shelter, supervision, and care for the physical and mental health of that person. Neglect causes or is likely to cause harm to a person. NMAC 7.1.14.7(S).

Exploitation is defined as an unjust or improper use of a person's money or property for another person's profit or advantage, financial, or otherwise. NMAC 7.1.14.7(K).

Suspicious Injuries: Suspicious injuries are not defined in the New Mexico Administrative Code; however, some examples of suspicious injuries include:

- A patterned bruise, no matter its size, that is in the shape of an identifiable object such as a belt buckle, shoe, hanger, etc.
- Unexplained serious injuries or multiple bruises, cuts, abrasions.
- A spiral fracture.
- Dislocated joints (e.g. shoulders, fingers).
- Facial or head injuries (e.g. black eyes, injuries to the scalp).
- Bruising to an area of the body which does not typically or easily bruise (e.g. midline stomach, breasts, genitals or middle of the back).
- Injuries that are not consistent with what is reported to have happened, for example:
 - bruising to the inner thighs are explained to have been sustained in a fall that happened in the driveway.
 - o injuries explained as caused by self-injury to parts of the body the consumer has not previously injured or cannot access.
 - Injuries are explained as having been caused by another consumer, but the consumer has no history of such behavior or there is no documentation of an incident.
- A pattern of injuries such as injuries recurring during certain shifts or at certain times of the day.
- The explanation for how an injury occurred is not reasonable, probable, or is unlikely.
- Petechiae (definition: pinpoint round spots appearing on the skin as the result of bleeding under the skin or the result of minor hemorrhages caused by physical trauma).
- The consumer is repeatedly injured when certain staff is working, even when there is an explanation of how the injury occurred.

Environmental Hazard: A condition in the physical environment which creates an immediate threat to health and safety of the individual. NMAC 7.1.14.7(J).

Immediate Action and Safety Plan (IASP)

The need for an Immediate Action and Safety Plan (IASP) is assessed in all types of settings and regardless of the investigation findings. Some examples of protective services include:

- Arrange for an adult to stay somewhere temporarily or a permanent move;
- Change the adult's phone number or email address;
- Change locks at the adult's residence;
- Provide domestic violence shelter information or other domestic violence resources;
- Offer and assist with safety planning;
- Offer information on obtaining a protection order (restraining order, stalking order, sexual assault order);
- Assist with obtaining medical assistance or assessment;
- Staff person accused of abuse is put on administrative leave or moved to a different position.

Abuse Reporting

According to Dr. Nora Baladerian in the 2012 National Survey on Abuse of People with Disabilities,⁴ "Nearly half of victims with disabilities did not report abuse to authorities. Most thought it would be futile to do so. For those who did report, nearly 54% said nothing happened. In fewer than 10% of reported cases was the perpetrator arrested."

Dr. Baladerian's research indicated 87% of the respondents reported verbal-emotional abuse, 51% reported physical abuse, 42% reported sexual abuse, 37% reported neglect, and 32% reported financial abuse.

We know through Dr. Baladerian's research and others that reporting of abuse, neglect and exploitation is low. Some reasons for low reporting include; thinking the police

Categories of Protective Services

- Advocacy
- Alternative living arrangement
- Counseling
- Legal Services
- Medical Services
- Mental state examination
- Physical state examination
- Removal of staff involved

⁴ The National Survey on Abuse of People with Disabilities, authored by Dr. Nora Baladerian, Thomas F. Coleman and Jim Stream for the 2013 Spectrum Institute, disability and abuse project.

wouldn't be able to help, not wanting the offender to get in trouble, and fear of reprisal. Abuse reporting increases significantly when family members are involved in their loved one's care, so educating family members and guardians of individuals with I/DD is crucial in increasing reporting.

In 2013, 96% of individuals with a disability who were victims of violent crime could identify their perpetrator. Of those, 41% were victimized by an acquaintance, 31% were victimized by a stranger, and 15% were victimized by an intimate partner. An acquaintance is defined as someone who well or casually known to the victim, including caregivers.⁵

The Incident Management Bureau maintains a 24-hour Hotline for reporting abuse at (800) 445-6242. See NMAC 7.1.14 for Incident Reporting Requirements for Community Providers.

Dr. Baladerian developed "A Guide on Responding to Suspected Abuse of People with Developmental Disabilities" with ten tips for family members.⁶

- 1. Know and believe that abuse can happen to your loved one.
- 2. Become familiar with the signs of abuse. Any signs of injury, changes in behavior, mood, communication, sleep or eating patterns are included.
- 3. When you suspect something is wrong, honor your feeling and take action immediately.
- 4. When you suspect abuse, call a child or adult protective services agency and the police.
- 5. Do not discuss your suspicions with anyone at the program where you believe abuse is occurring, as they may deny any problems, punish your loved one, and attempt to destroy any evidence that may exist.
- 6. Remove your loved one from the program immediately.
- 7. If there are injuries or physical conditions, take your loved one to a physician, not only to diagnose and treat the condition, but create documentation of your visit and the findings.
- 8. Create a document in which you write all of your activities. Begin with when you first suspect abuse or neglect. Where were the signs or signals you noticed? Write the dates of these, and if there were injuries, detail what they were, their appearance, and where on the body you saw them. If staff gave an explanation, record this in your file.

⁵ Bureau of Justice Statistics, Crime Against Person with Disabilities, 2009 - 2013 Statistical Tables, (U.S. Department of Justice, 2015), https://www.bjs.gov/content/pub/pdf/cap0913st.pdf.

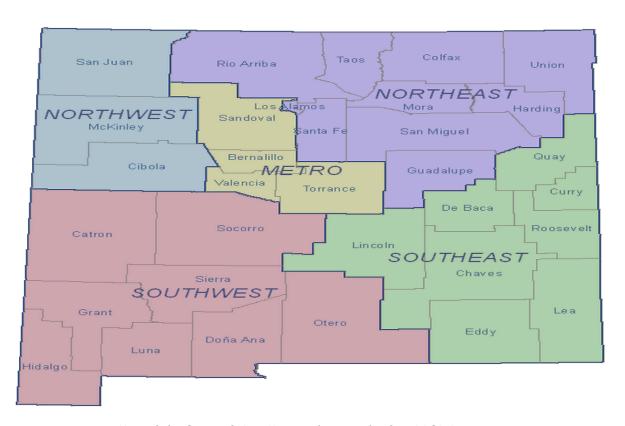
⁶ A Guide on Responding to Suspected Abuse of People with Developmental Disabilities, by Dr. Nora Baladerian through the Disability and Abuse Project.

- 9. Notify the Regional Center representative of your findings, suspicions and actions or your disability program in your state.
- 10. Get a police report. Contact the Victims of Crime program in your area and seek their support for reimbursement of costs and therapy for the family.

DDSD Regional Offices

For purposes of service delivery, the Department of Health (DOH), Developmental Disabilities Supports Division (DDSD) has divided the state of New Mexico into five Regions. Each Regional Office is responsible for the delivery of DOH services in their region. The IMB has established an investigative presence in each Region to correspond with their DOH counterparts in the other DOH Divisions and Bureaus.

This allows the Investigators to become familiar with the Community-Based Service Providers in their Region, and to work collaboratively with the local providers and the Developmental Disabilities Supports Division (DDSD) staff to address issues specific to their programs, and their unique population of individuals.

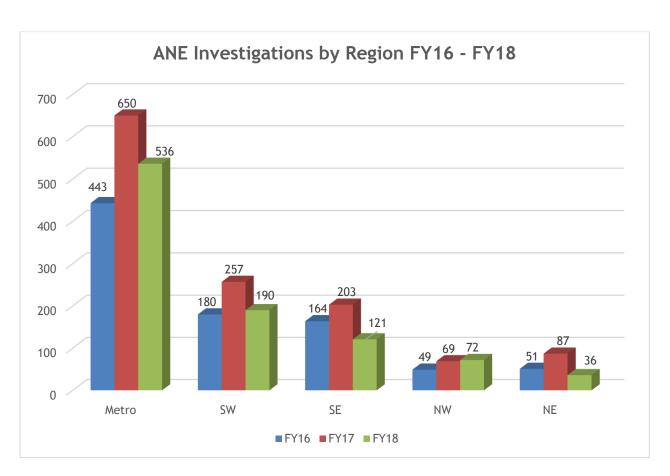


Map of the State of New Mexico showing the five DDSD Regions.

The following graphs show the division of ANE investigations by Region for FY16 through FY18. Although there were minor variations in the percentage of investigations assigned in each Region of the state, the overall percentage change was relatively minor.

Metro, which includes Bernalillo, Sandoval, Valencia and Torrance counties showed a 17% decrease in the number of assigned cases, as did the SW, SE, and NE Regions. While the NW Region saw a 4% increase. However, the three year average for all Regions remained fairly consistent.

COMPARISON OF FISCAL YEAR 2016 thru 2018 DATA



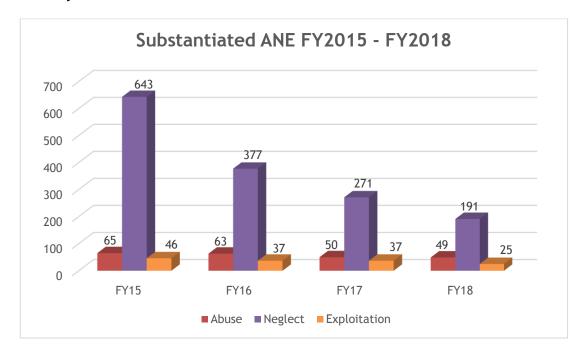
This chart shows the number of ANE investigations assigned in each region of the state for FY16, FY17 and FY18.

SUBSTANTIATED INVESTIGATIONS

At the completion of an IMB investigation, allegations of abuse, neglect or exploitation are either substantiated, which means the ANE occurred, as defined by the NMAC, and the Accused Person or Agency committed the ANE. Or, unsubstantiated, which means the ANE did not occur, or the Accused Person or Agency was not responsible.

Occasionally, Investigators may investigate and substantiate against an "unknown staff." It is important to acknowledge abuse, neglect or exploitation occurred, even if we're unable to identify who did it.

Placement on the Employee Abuse Registry (EAR) may occur when the abuse, neglect or exploitation rises to a certain level of severity as defined in New Mexico Administrative Code 7.1.12. This rule applies to a broad range of New Mexico providers of health care and services and employees of these providers who are not licensed healthcare professionals or certified nurse aids. After three years, the person may petition to be removed from the EAR, and must demonstrate rehabilitation in the area of ANE they were substantiated in.



This chart shows a comparison of <u>substantiated</u> ANE allegations investigated in DD Waiver and the Mi Via Self-Directed Waiver programs over a four-year period.

⁷ NMAC 7.1.12 Employee Abuse Registry

Between SFY2015 and SFY2018, there was a continuing decline in the percentage of substantiated Neglect cases. In July 2014, the NMAC definition of Neglect changed. The current definition of Neglect states, "Neglect causes, or is likely to cause harm, to a person." It's easy to determine when Neglect causes harm to a person. The harder question is trying to determine when Neglect is <u>likely</u> to cause harm. An investigation into an allegation of Neglect requires an analysis of the "...likely risk of harm" to the consumer. Risk of harm refers to clinically significant harm, which has not yet occurred but is <u>likely to occur</u>, given risk factors identified in the present. The level of future risk is identified as likely (probable), not just possible (may occur). The probable harm will have a significant detrimental effect on the consumer if it does occur. Many times, Investigators rely on a consultation with a medical professional to help make this determination.

In 2015, Neglect comprised 85% of all substantiated cases investigated by IMB. Comparatively, Abuse and Exploitation comprised 9% and 6% respectively. This raised concerns that Investigators were not applying the definition of Neglect correctly. IMB conducted additional training for Investigators on how to analyze an allegation of Neglect (i.e. that Neglect causes or is likely to cause harm). Subsequently, in 2016, substantiated Neglect decreased to 77% of all substantiated cases. In 2018, substantiated Neglect decreased to 62%. We believe the decrease in substantiated Neglect is partially a result of Investigators doing a better job of analyzing the "risk of harm" associated with Neglect investigations. Other factors may include targeted training by DDSD and stricter enforcement of existing rules by the Quality Management Bureau (QMB).

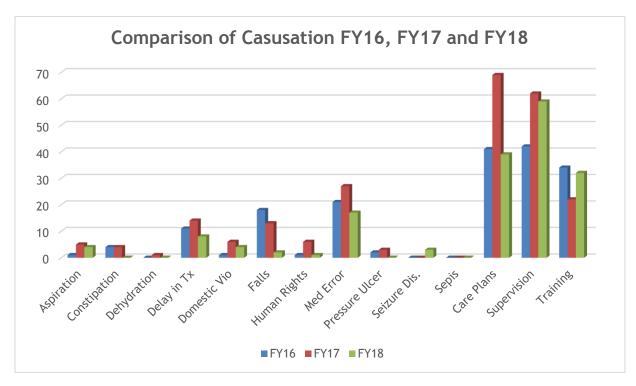
Causation

The new IMB database was rolled out on June 27th, 2015 and since then IMB has been collecting information on the causes and contributing factors of ANE; more specifically related to Neglect. Reports/allegations of Neglect accounted for 62% of all IMB

investigations in FY18. It is therefore imperative to use the IMB database to try and determine the most common causes of neglect, and take steps to mitigate those causes.

The "causation" tab in the IMB database is a quick-reference guide to determine the most common causes of Neglect. Now that IMB has two years' worth of data, we can use this information to guide training initatives around the state, or take other actions to reduce the prevelance of Neglect.

IMB has identified 14 common causes of Neglect, including the "fatal five;" the five most common conditions that lead to premature death of people with I/DD.⁸ The 14 causes include; aspriation, constipation, dehydration, delay in medical treatment, domestic violence, falls, human rights abuses, medication errors, pressure ulcers, seizure disorder, sepsis, failure to follow healthcare plans, lack of appropriate supervision, and lack of training.



This graph shows a comparison of substantiated Neglect in FY16, FY17 and FY18. The top three causes of Neglect in FY2018 include failure of staff to follow healthcare plans, lack of appropriate supervision for the client and failure of the Agency to provide proper training.

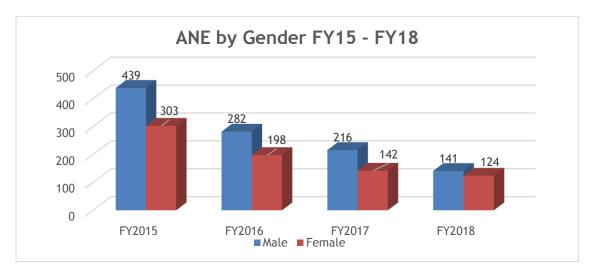
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⁸ According to the National Alliance for Direct Support Professionals, the "fatal five" includes; aspiration, bowel obstruction, dehydration, gastroesophageal reflux disease and seizures.

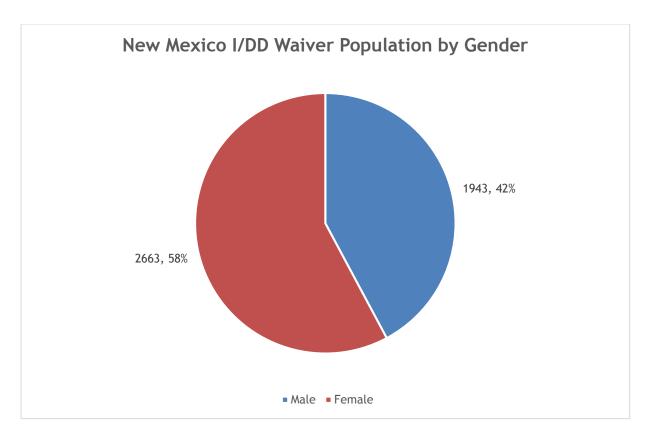
Gender

People with intellectual disabilities can be both the victims and perpetrators of sexual violence (often termed sexual abuse). Prevalence rates of sexual violence against people with I/DD are high when compared with the experience of the general population. According to US Department of Justice statistics, people with intellectual disabilities are sexually assaulted at a rate seven times higher than those without disabilities. While people with intellectual disabilities experience sexual violence in many of the same ways as the general population, they may encounter additional issues related to their impairments and/or the social environments in which they live. These can include increased vulnerability, questions around ability to consent to sexual activities, social attitudes about intellectual disability and sexuality, and restricted access to suitable support and recovery services.

A comparison of how gender plays a role in the victimization of people with I/DD may help develop insight on how to prevent certain kinds of abuse. Data from the previous three years shows that males are more likely to be victims of Neglect than females, although in FY2018 the gender gap decreased significantly over previous years. In New Mexico, males represent 16% more of the I/DD Waiver population. This may partly explain why we see higher incidence of neglect.



This graph shows the number of substantiated ANE allegations over a four-year period. Males are consistently represented more often than females. Males make up 16% more of the I/DD population in New Mexico than females. The Gender gap has decreased significantly over the past four-years.



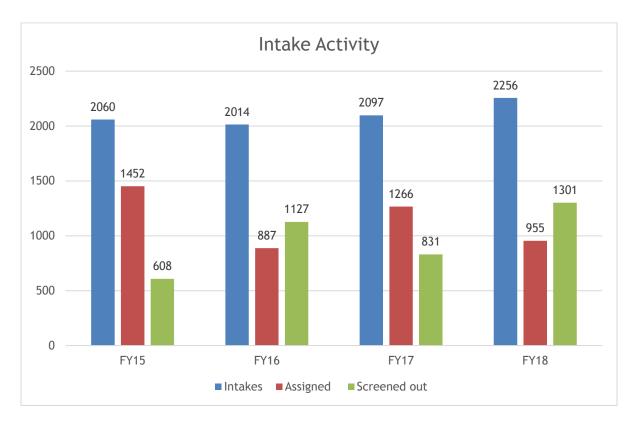
The New Mexico I/DD population served by the DD Waiver, Mi Via Self-Directed Waiver and the Medically Fragile Waiver has a 16% higher population of males than females.

Case Assignments

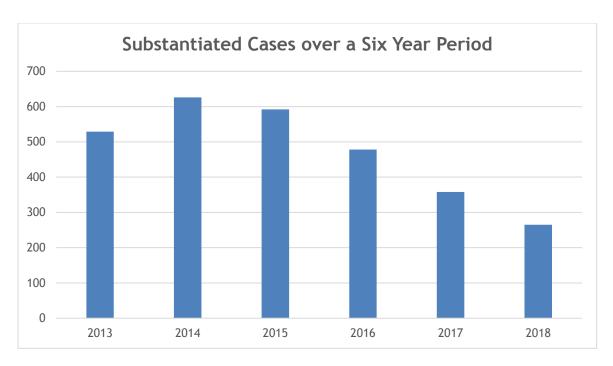
Incident reporting has remained consistent over the past three years. As incidents are reported to the Hotline, IMB Intake staff screen the reports to ensure IMB has the jurisdiction and authority to conduct an investigation. Jurisdiction refers to whether the alleged victim is served under the Developmental Disabilities waiver, the Mi Via (self-directed) waiver, or the Medically Fragile waiver. Authority refers to whether the allegation meets the definition of abuse, neglect or exploitation, as defined by the New Mexico Administrative Code.

Beginning in FY2015, IMB began refining the screening process, to ensure the health and safety of the alleged victim was assured pending the screening process and case assignment, speeding up the decision-making process, and working with Provider agencies to more quickly get information in order to make an informed decision.

Each Quarter, IMB conducts a quality assurance review of a sample of reports. The review looks at timely reporting, the use of a consultant, when necessary, timely screening, if the appropriate screening decision was made, assigning an appropriate severity level, obtaining relevent information from the Reporter, obtaining an adequate Immediate Action and Safety Plan, identifying if a late/fail notice is necessary and proper notification of the screening decision to the responsible provider agency. This information is then used to provide additional training to the Intake staff to improve the operation of the Hotline and ensure cases are assigned appropriately.



This graph shows the number of referrals received by Intake, the number of cases assigned and the number of cases screened out over the past four years.



The relatively steep drop in substantiated cases of abuse, neglect and exploitation can be explained, in part, by changes to the NMAC in July 2014 that redefined Abuse, Neglect and Exploitation. Investigators have been given additional training in analyzing the, "…likely risk of harm" in Neglect cases, which comprise the majority of IMB investigations. Finally, survey's conducted by the Quality Management Bureau are designed to identify issues before they result in an allegation of ANE.

<u>Summary</u>

In July 2014, the Incident Management Bureau promulgated a significant change in the New Mexico Administrative Code. These changes, which include an Intergovernmental Agreement (IGA) with the states' Aging and Long-Term Services Department, gave IMB the sole authority to investigate abuse, neglect and exploitation in the Developmental Disabilities Waiver, the Mi Via Self-Directed Waiver and the Medically Fragile Waiver. These rule changes also eliminated the investigation of law enforcement and emergency services contacts within this population, unless there was a clear report/allegation of ANE.

Neglect continues to be the largest category of ANE substantiated by IMB; the failure of a caregiver to provide the services necessary to maintain the health and welfare of the consumer. It's not unusual Neglect is the highest category of ANE, given the high level of supports our clients require. Supervision, medication administration, following

healthcare plans, etc. all require staff to be highly trained and follow strict guidelines for the care and support of the I/DD individuals they work with.

By using IMB data to look for trends, we can work with our DDSD partners to target specific training to direct care staff, or identify emerging issues in a particular region of the state.

For example, in July 2018, IMB identified 21 investigations where staff failed to properly secure a wheelchair prior to transporting the client in a vehicle. In each case, the wheelchair fell, injuring the client. IMB determined that in nearly every case, the "trained" staff were not required to perform a skills test to demonstrate they knew how to properly secure a wheelchair prior to transporting the person. IMB worked with the DDSD Clinical Services Bureau to develop an alert for Provider agencies, recommending that they include a skills demonstration as part of their transportation training.

IMB will continue to track the 14 most common causes of Neglect, including the "fatal five;" the five most common reasons people with I/DD die prematurely. By tracking Neglect investigations that involve these causes, we can more quickly identify and respond to providers that have high incidences of these, and provide remedial training, technical assistance or enforcement of existing rules to reduce incidents of Neglect.

Increased reporting of ANE is a key factor in keeping individuals with I/DD safe. There are many indviduals with I/DD who are vulnerable to abuse, neglect and exploition, who do not receive services through the Developmental Disabilities waiver, Mi Via waiver or Medically Fragile waiver. Through increased educational efforts targeted at family members, guardians, medical professionals, stakeholders and the general public, our goal is to continue increasing awareness and reporting of suspected abuse, neglect and exploitation for the entire I/DD population.

Also, through complete, thorough, and unbiased investigations, we can identify and hold accountable those individuals who abuse, neglect or exploit our most vulnerable citizens.