Why are individuals with intellectual and developmental disabilities (I/DD) vulnerable to abuse?

Individuals with 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 or fear the change in living arrangements.

In 2015

1,452 investigations of abuse, neglect or exploitation were conducted.
592 allegations of abuse, neglect or exploitation were substantiated.
434 consumers were determined to have been the victim of abuse, neglect or exploitation.
Why are individuals with intellectual and developmental disabilities (I/DD) vulnerable to abuse?

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. All people who work with individuals with I/DD are mandatory reporters of abuse. 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). The Intake Specialist provides notification to certain individuals and entities, including the consumer’s case manager. The Responsible provider is responsible for delivery of the immediate action and safety plan (IASP).

- Once it is determined that a complaint meets the definition of abuse, the case is screened in and an Investigator is assigned. The Investigator makes a mandatory report to law enforcement if they believe a crime has been committed. The Investigator will begin an investigation into the nature and cause of the abuse, while continuing to assess the appropriateness of the IASP.

- 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 corrections/preventive actions are individually tailored to each situation, whether or not abuse has occurred. 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: mandatory abuse
reporting training for all program staff, updating the Individual Service Plan, and re-evaluating the need for increased supervision.

If an investigation is Substantiated, IMB may refer the investigation to:

- **Law Enforcement**: Notified anytime there is reasonable cause to believe that a crime has been committed. This often occurs at the beginning of an investigation.
- **Developmental Disabilities Supports Division**: Holds the state contract with all community based providers, and is responsible for corrective action functions for providers of services in individuals with developmental disabilities.
- **Licensing Boards**: Responsible for issuing sanctions, fines or other corrective action to licensed professionals (e.g. Nurses, Licensed Counselors, Social Workers, Physicians and Dentists).
- **Medicaid Fraud Unit**: Also investigates and prosecutes physical, sexual and financial abuse or neglect of consumers who receive Medicaid funding.
- **Employee Abuse Registry**: Established on January 1, 2006, the EAR is an electronic registry of persons with Substantiated registry referred abuse, neglect or exploitation that meet severity standards. It supplements other pre-employment screening requirements such as Caregiver Criminal History Screening (CCHS).
- **Internal Review Committee (IRC)**: Oversees the performance of community based providers to assure qualified providers are providing appropriate services under various Department contracts and agreements, including the DD Waiver, Mi Via Waiver and Medically Fragile Waiver.
In SFY15 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.

**Who do we serve?**

DHI and its partners provide supports and services to adults who meet eligibility criteria for the Medicaid DD Waiver and Mi Via Self-Directed 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. This 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 or fetal alcohol syndrome. Some people with developmental disabilities also have significant medical or mental health needs. In 2015, over 4,900 adults were enrolled in I/DD services through the DD Waiver or Mi Via Self-Directed Waiver programs.

In 2015, the overall number of investigations in the DD Waiver and Mi Via Self-Directed Waiver programs remained similar to the 2014 numbers. However, the new NMAC Administrative Rules enacted on July, 2, 2014 removed the requirement for providers to report Law Enforcement and Emergency Medical Service contacts with consumers, thereby reducing the overall number of calls received by Intake.
Mission Statement

IMB exists to assure the health, safety, and well-being of individuals served on the DD waiver by investigating allegations of abuse, neglect, exploitation, suspicious injury, environmental hazard, and death.

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. NMAC 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 NMAC, 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:
  - bruises to the inner thighs are explained to have been sustained in a fall that happened in the driveway.
  - 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 adults 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, 1 “Nearly half of victims with disabilities did not report abuse to authorities.

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1 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.
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. Abuse reporting increases significantly when family members are involved in their loved one’s care, so educating family members of individuals with I/DD is crucial in increasing reporting.

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.²

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.

² 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.

This chart shows the percentage of **substantiated** ANE allegations investigated in DD Waiver and the Mi Via Self-Directed Waiver programs in FY15.

For purposes of service delivery, the Department of Health 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 Providers in their Region, and to work collaboratively with the local providers and the Developmental Disabilities Support Division (DDSD) staff to address issues specific to their programs, and their unique population of consumers.
This chart shows the percentage of ANE investigations assigned in each region of the state for FY15.
This graph shows the number of investigations received and assigned in comparison to the DD waiver and Mi Via waiver population in each region.

While males and females were equally likely to become victims of substantiated ANE overall, in FY2015 females were slightly more often to be victims of sexual and physical abuse, and more males were victims of neglect. Exploitation was nearly equal.
Summary

As evidenced by the above chart, substantiated allegations of abuse, neglect and exploitation of individuals with I/DD is on the increase; however, we believe this is most likely due to an increase in reporting and an increase in the Waiver population. With the changes to the NMAC rules in July 2014, the IMB has put significant resources toward educating community based providers about their responsibility to report. While the prevalence of ANE is too high, we believe we are on the right track. Without a high rate of reporting, we aren’t able to address the underlying issues that lead to ANE. Through continued work with our partners, community based providers and other stakeholders, we will continue to work to reduce the incidence of abuse, neglect and exploitation in the I/DD population.

By far the biggest category of ANE is neglect; the failure of a caregiver to provide the services necessary to maintain the health and welfare of the consumer. Using IMB data to look for trends, we can work with our DDSD partners to target specific training to direct care staff. In the future, the IMB will track the “fatal five.” The fatal five are the five most common reasons people with I/DD die prematurely. The fatal five includes aspiration, constipation, dehydration, seizures and sepsis. By tracking neglect
investigations that involve one of the fatal five maladies, we can more quickly identify and respond to providers that have high incidences of these, and provide some remedial training.

Through increased education efforts targeted at family members, guardians, medical professionals, stakeholders and the general public, we aim to continue increasing reporting of suspected abuse, neglect and exploitation.

In 2016, the IMB will begin certifying community based provider trainers, to teach ANE reporting in a face-to-face adult learning environment. Direct care staff are already required to have ANE reporting training annually. This project will give us an opportunity to ensure the material is being taught in accordance with the curriculum and consistently throughout the state.

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