FACT SHEET

Intellectual and Developmental Disabilities

NATIONAL INSTITUTES OF HEALTH

- **Intellectual disability** refers to a group of disorders characterized by a limited mental capacity and difficulty with adaptive behaviors such as managing money, schedules and routines, or social interactions. Intellectual disability originates before the age of 18 and may result from physical causes, such as autism or cerebral palsy, or from nonphysical causes, such as lack of stimulation and adult responsiveness.
- **Developmental disability** is a severe, long term disability that can affect cognitive ability, physical functioning, or both. These disabilities appear before age 22 and are likely to be life-long. The term "developmental disability" encompasses intellectual disability but also includes physical disabilities. Some developmental disabilities may be solely physical, such as blindness from birth. Others involve both physical and intellectual disabilities stemming from genetic or other causes, such as Down syndrome and fetal alcohol syndrome.

Yesterday

- Historically, people with intellectual disabilities did not live as long as others and were at increased risk for health problems. Children often died because their condition could not be diagnosed. It was common for people with intellectual disabilities to be institutionalized, and treatments were either nonexistent, ineffective, or harmful.
- Until the 1960s, screening methods to test newborns for many developmental disabilities were not yet available.
- For example, in the mid 1970s, more than 1,000 U.S. children each year acquired an intellectual disability shortly after birth because of hypothyroidism—the body's failure to produce sufficient amounts of thyroid hormone, essential for normal brain development. Although the hormone could be supplied artificially, the condition typically went undiagnosed until after permanent brain damage had occurred.
- A large study funded by NIH in the early 1970s showed that hypothyroidism could be easily detected, and treated within two weeks after birth, before any brain damage resulted. Soon, every state required thyroid hormone screening. Each year in the United States, roughly 1,000 cases of intellectual disability due to insufficient thyroid hormone are prevented.
- In the 1970s, *Haemophilus Influenzae* Type B (**Hib**), a bacterial disease that causes meningitis, was the leading cause of acquired intellectual disability. No means existed to prevent infection from Hib, which most often struck children from 6 months to 2 years old. On average, 1 in 10 infected children died from Hib meningitis, 1 in 3 became deaf, and 1 in 3 was left with an intellectual disability.
- Researchers at NIH developed **a vaccine for Hib**. Their work has virtually eliminated Hib meningitis from the developed world.
- Intellectual disability also can be acquired from **environmental exposure**. It was not known in the early 1970s that exposure to even small amounts of lead in the environment could have an adverse effect on the developing brain. At the time, more than 10 million children had blood lead levels high enough to affect their cognitive functioning. NIH-funded research linking elevated lead levels to lower intelligence test scores led to federal laws banning lead as an ingredient in paint and as an additive in gasoline, which reduced the chances that children would be exposed to this toxic metal.

Today

- Testing for thyroid hormone is one example among dozens of **screening tests** to identify and treat babies at risk of a congenital disorder. In 2000, 35 percent of

states screened for fewer than five conditions; by 2009, 49 states screened for 21 conditions or more.

- NIH supported researchers have shown that therapy and training techniques that focus on communication and behavior can be effective tools for people living with intellectual disabilities. In the first scientific evaluation of a behavioral therapy for toddlers with autism spectrum disorders, researchers compared two groups of children 18 to 30 months old. One received intensive, therapy emphasizing interaction and language skills, the other group received therapy available at community care centers. After two years, children in the intensive intervention group had increased their IQ scores by 17 points, compared with 7 in the other group; they were also less likely to be diagnosed with autism on reassessment.

Tomorrow

- The NIH is supporting the development of new technologies for newborn screening. The goals are to develop fast, reliable, and cost-effective means to screen newborns and to expand the number of conditions these tests can assess. Such screening makes it possible to begin treatment early, when chances for success are greatest.
- Research into the causes and early diagnosis of intellectual disabilities is a priority of the NIH-sponsored Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers (https://www.nichd.nih.gov/research/supported/eksiddrc.cfm). Researchers affiliated with these centers conduct studies to better understand the causes of such disorders and to pursue new avenues for treatment. Investigators at one center, for example, identified a source of adult stem cells in the brain. Such cells, which can develop new tissue, could one day be used to delay or prevent developmental diseases.
- Health disparities in survival and access to care are another priority for NIH research. People from disadvantaged backgrounds are less likely to receive screening services, diagnostic evaluations, or treatment interventions. Future studies will seek to identify factors that contribute to these disparities and develop new approaches that ensure equal access to early screening, therapeutic services, and treatment.
- Fragile X syndrome affects one in 2,500 births, resulting in intellectual disability, sleep problems, attention deficit disorder, aggression, and compulsive behavior. NIH-funded scientists working with mice having the same genetic mutation found in Fragile X syndrome learned that the mice have increased activity in the metabotropic glutamate receptor (mGluR), which sits atop brain cells. Researchers hope that drugs that block the mGluR receptor might one day be used to lessen the disorder's effects in humans. Advances in screening for this disorder also may one day give doctors a cheaper, more precise test for diagnosing the condition.
- Hypoxic ischemic encephalopathy—loss of blood or oxygen to an infant's brain during birth— may lead to brain damage or death. Researchers supported by the NIH discovered that lowering a baby's body temperature in the first six hours of life could help prevent disability. NIH is supporting studies to learn how best to use this new technique so that it soon may be used routinely.
- Duchenne muscular dystrophy occurs in about 1 in every 3,500 males. Symptoms include muscle weakness and difficulty walking and talking. Death usually occurs by age 20. In dogs with a canine form of Duchenne muscular dystrophy, researchers used DNA-like molecules called morpholinos to cover up the genetic error that causes the disease. The treatment restored functioning to the skeletal muscles, but was unable to prevent deterioration of the animals' hearts. Researchers are now seeking more effective ways to deliver the treatment to the heart.

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