

NEW HORIZONS UN-LIMITED INC.
"Shaking the World in a Gentle Way"

NHU Report on the Prevention of Disabilities
Spring 2015

We all know to move forward on any problem facing mankind requires research, and collection of data is absolutely essential to research. We are stating, in order to protect children of the future, a serious program of collecting all relevant data can wait no longer.

New Horizons Un-Limited is an organization of disability advocates concerned about the personal impact of disability. This Report is a Call to Action in protecting newborns, their parents and society from disabilities by acting to establish a more comprehensive data collection at birth. This is a call to broaden the scope of data collected through the U.S. Standard Certificate of Live Birth. This update of data systems is necessary to more effectively meet current research needs for the purpose of preventing disabilities.

This report has been sent to the U.S. DHHS, NCHS, CDC, national institutes of health and disability, legislative health committees, and other medical and disability organizations who share our great concern for a more adequate scientific approach to collecting data at birth of each child in the U.S. in the interest of preventing lifelong disability for the future generations of our children.

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Report Synopsis

This Report is a Call to Action for leadership in protecting newborns, their parents and society from avoidable, devastating, lifelong, Developmental Disabilities, such as Autism Spectrum Disorders (ASD) and Cerebral Palsy (CP), to establish a more comprehensive data collection before birth, through the birth process, and directly after birth. This is a call to review, improve and broaden the scope of data collected through the U.S. Standard Certificate of Live Birth. This update of data systems is necessary to more effectively meet current research needs for the purpose of preventing Developmental Disabilities.

It is also a call for an open and honest dialog between medical professionals, government sponsored support and research and the individuals affected by Developmental Disability and their families.

Each time a child is born with a disability, we must ask ourselves, "With all our amazing medical advances, why are we still unable to prevent lifelong, incurable, devastating, Developmental Disabilities?"

We cannot begin to prevent Developmental Disabilities, because, as reported by the Center for Disease Control and Prevention (CDC), there is a lack of data and research regarding conditions responsible for the increasing prevalence in the past decade of disability and what is needed to identify these causes. (1)

Although medical science does acknowledge a complex mix of risk factors prevalent in the research of Developmental Disabilities, the CDC claims for over half of the instances of these disabilities, causes have not been identified. The fact is there are various ways that the developing brain may be subject to stress, infection, endure trauma or injury at birth to cause the abnormal formation or injury of the brain, however, there are road blocks and much research to be done to link causes with effects of Developmental Disabilities.

We agree with the CDC that as a society, we cannot find causes, until we are effectively collecting data at birth to adequately identify causes or risk factors. (2) Without data, there is not science, there may only be opinion.

- This Prevention Report illustrates the epidemic of Developmental Disabilities in the U.S in the past decade, how these conditions are incurable and lifelong, the extraordinary cost of disability, and how data at birth could assist in identifying causes and risk factors to prevent them.

- The Prevention Report illustrates how in the last 30 years there appears to have been a shift in focus and effort away from the actual prevention at birth of Developmental Disabilities. Prevention appears to have been ignored in policy, legislation, medicine, research and most of all, data collection which has appeared to hinder efforts to find cause.

1. In 1991 the focus of prevention shifted from actual prevention at birth to concentrate on early childhood identification and intervention. Although identification and intervention are extremely important, prevention at birth has received less effort and research as a result. (3)

2. Since 1999 doctors were no longer mandated by legislation to monitor and report developmental disability; only diagnoses of birth defects have been mandated by states for registry. (4) Developmental Disabilities are the focus of this report.

- The report shows, as reported by the National Vital Statistics' measure of health research, there is not enough data to accurately identify causes or all the risk factors suspected at birth. (5)

1. DHHS, CDC, and NCHS, have done a remarkable job with the past data from the standard certificate of live birth, however, the last review of the standard was 13 years ago. Data collected is vague and not in sync with the rapid advances in medicine for today's research needs. (6)

2. With the recent passage of the Autism CARES Act of 2014, more data collection for research will be required from existing CDC research programs related to these disabilities; although these are special, necessary programs, they do not collect data at birth. (7) Much of what CDC collects in these research surveys is also collected by education and census surveys; some of which is redundant. We recognize we may never be able to collect all the data, but for the abnormal birth, the lack of comprehensive data collection is marginalizing human life by failing to concentrate on data resources for prevention.

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The U.S. Standard Certificate of Live Birth is the infrastructure of data collection along with medical birth records that are sent to state and federal vital statistics collection agencies. The CDC confirms that broadening the scope of data collected at the time of birth is paramount for research needs. For instance, more comprehensive data should include other factors such as prenatal care, environmental factors, over the counter or prescribed medications, and advances in medical obstetric practices, any of which may hold the key to what causes these disabilities and how we may prevent them. (8)

Since the last update of the U.S. Standard Certificate of Live Birth in 2003, almost all 50 states have adopted the standard. With ongoing advances in automation of record keeping, medical and data collection agencies at the local, state and federal level will be better able to more efficiently update to the revised standard.

Many developmental disabilities are from injury or an anomaly before, during, or after birth, (for which, we may or may not know cause) which damages or causes malformation of the infant's vulnerable developing brain. The resulting disabilities, such as ASD, vision impairment, hearing impairment, intellectual disabilities, learning disabilities, ADHD, and CP affect several areas of child development and impair the child's performance and roles in society to affect everything the individual tries to attain in his or her lifetime. (9) (10)

CDC recently estimates about in 1 in 6 children from age 3-17 have one or more developmental disabilities. (10) In the last couple of decades there has also been a large increase in elective obstetric procedures which also use stimulants, analgesics and anesthetics. Is there a connection? What are the long term effects?

With the direct costs for each child over a lifetime estimated at over \$1 million (in 2003 dollars for intellectual disability and cerebral palsy,) each year tens of billions of dollars (estimates for the cost of Autism vary greatly) are added to our societal debt. Lifetime indirect costs (i.e. productivity losses) per person are estimated two to five times the amount of direct costs. The devastating physical, social and economic costs to each individual, family and society, make prevention of Developmental Disabilities extremely urgent! (11)

The unprecedented rise of Developmental Disabilities in children in the U.S. requires a mandate:

- **This Prevention Report is a call for the USDHHS, NCHS and CDC to establish a new review panel** including medical professionals and researchers to develop an updated revision of the current U.S. Standard Certificate of Live Birth (last revised 2003) to more effectively collect vital, statistical data from before, during and after birth for a more scientific approach for the purpose of preventing disability. (12)

The U.S. Standard Certificate of Live Birth could be revised to be more specific in documentation. In addition to what is asked on the current form, we suggest consideration of broadening data to include:

- ALL neurological dysfunctions, not only "serious dysfunctions or seizure."
- All birth injuries, not only "significant" injuries.
- Name or type of all medicines, over the counter and prescribed, stimulants, analgesics or anesthetics used in addition to those currently required, including specific doses.
- A place to clarify Apgar score.
- A place to add specific information about presentation at birth or if other abnormal conditions are present to list them rather than check a box that represents many choices.

- **This Prevention Report is a call to revise legislation** that each state accepts this new minimum standard certificate and to update medical and data collection agencies for recording the new standard for uniform, reliable data collection.

- **This Prevention Report is a call for education and training for hospitals, doctors, nurses, and other attendants of birth to lead the call for prevention to observe and protect the unborn;** to review and educate all attendants of birth, advise parents for healthy prenatal care, measure quality of care outcomes, and identify and prohibit known obstetric techniques that put children at risk of disability. This is a call to continue educating medical staff of the importance to adequately record data for the revised standard of live birth for research for prevention of disability.

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- **This Prevention Report is a call for more funding of education and assistance programs** for students and future parents about healthy prenatal care, risk factors of disability and the importance of their role in protecting the unborn.

Given the rise in this past decade of the prevalence of lifelong, incurable, developmental disabilities, the great cost and devastation to our children, families, and society, the inability to find definitive causes, and the consideration that a significant percent may be preventable, there is a great need to broaden research, which we know as a nation we must now pursue, to find the causes to prevent them. We are writing to ask the agencies listed below, including the CDC, to take action, in accordance with medical research needs, to update the collection of data before, during and after birth on the U.S. Standard Certificate of Live Birth, to identify ways to prevent these disabilities in the U.S. If data is not collected, any statements regarding cause of disability is opinion or guess and not research based science.

We must all, including government representatives, researchers, the medical community and parents take more responsibility to record data at birth, advocate for more awareness, and train for more education for a quality standard of health and care for parents and newborns, to ensure, at the very minimum, a safe entrance to life for each and every child born, allowing that during their lifetime, each child may realize their maximum potential without unnecessary devastating limitations from disabilities.

Why should we fund the unborn when we have other political priorities?

Children are not an expendable part of our community. Preventing disabilities means we care enough, now, to ensure our collective futures by attending to the protection of our children. (13)

A far greater effort must be made without delay so we may identify the causes and ways to prevent Developmental Disability from one more child, one more family, and to our society! If disability has not happened to you or your family, with these odds, disability can very well happen to your children or grandchildren, your nieces or your nephews.

Every year we delay 127,000 more children and their families are impacted. The time to act is today!

We urge you to review the following information which documents extensive instances of medical concern and identifies research needs to take administrative, legislative and regulatory action to identify and reduce exposure to the causes of disability.

This Call to Action for Prevention Report is from New Horizons Un-Limited is an organization of disability advocates concerned about the personal impact of disability.

Please let us know what is being done to save children from enduring the suffering of disability. On behalf of future generations of children, we thank you in advance for your attention and support of needed data collection and research to prevent disability.

This report has been sent to the U.S. DHHS, NCHS, CDC, national institutes of health and disability, legislative health committees, and other medical and disability organizations who share our great concern for a more adequate scientific approach to collecting data at birth of each child in the U.S. in the interest of preventing lifelong disability for the future generations of our children.

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Introduction

This Report is a Call to Action for leadership in protecting newborns, their parents and society from avoidable, devastating, lifelong, Developmental Disabilities, such as Autism Spectrum Disorders (ASD) and Cerebral Palsy (CP), to establish a more comprehensive data collection before birth, through the birth process, and directly after birth. This call is to review, improve and broaden the scope of data collected through the U.S. Standard Certificate of Live Birth. This update of data systems is necessary to more effectively meet current research needs for the purpose of preventing Developmental Disabilities.

This call is for an open and honest dialog between medical professionals, government sponsored support and research, and the individuals affected by Developmental Disability and their families.

Many Developmental Disabilities are from injury or an anomaly before, during, or directly after birth, (for which, we do not know the cause) which damages or causes malformation of the infant's vulnerable developing brain. Resulting Developmental Disabilities, such as ASD, Vision and Hearing Impairments, Intellectual Disabilities, Learning Disabilities, ADHD, and CP affect several areas of a child's development and impair the child's performance and roles in society to affect everything the individual tries to attain in his or her lifetime. (14) (15)

This report will focus on the prevention of Developmental Disabilities, with special emphasis on the prevention of the causes of birth anomaly or injury. While the prevention of Developmental Disabilities appears to have been ignored, there has been an overwhelming legislative, financial and medical effort to prevent birth defects.

Developmental Disabilities are the focus of this report.

We will be asking questions in this report. When a child is diagnosed with a developmental disability, the first thing we ask is, "What is the cause?" What happened for this to occur? Is it genetic? Was there an infection? Were there risk factors involved? Were there complications at birth? Could the parent or doctor have done anything to prevent the condition of the newborn?

How will we answer these questions, if we have not taken and do not begin to take, specific data at birth? How will we answer these questions, if we do not try to research the long term effects of medications, obstetric procedures, fertility interventions, etc. from birth?

Developmental Disabilities, an epidemic.

Why in the past decade and a half has there been a significant increase in the number of children exhibiting Developmental Disabilities, such as ASD, Vision Impairment, Hearing Impairment, Intellectual Disabilities, Learning Disabilities, ADHD, and CP with resulting motor disabilities and developmental delays?

How much do we not know about the causes of these Developmental Disabilities?

Developmental Disabilities

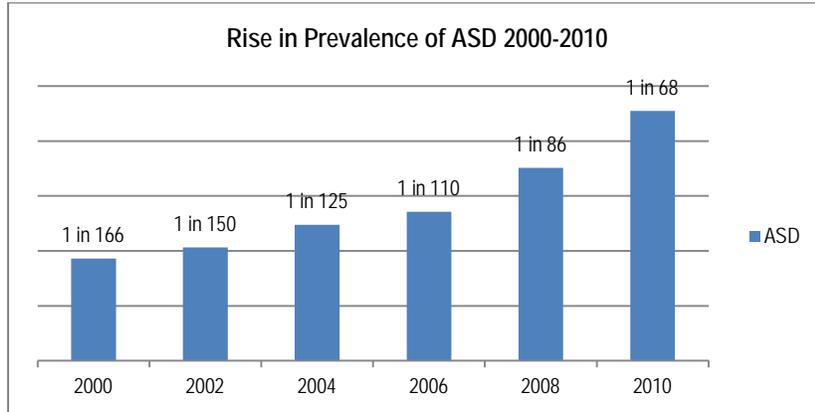
The 2011 Pediatrics report states research revealing "changes in the prevalence of developmental disabilities are scarce." There are a few studies on individual disabilities, but data examining the impact of the full range of developmental disabilities are unavailable. The report based data collected from a study from **1998-2008** by the National Health Interview Surveys (NHIS), surveyed parents who reported diagnoses of Developmental Disabilities. This data showed an increase over the 12 year period revealing estimates in 2008 that about 1 in 6, or over 15% of children aged 3 through 17 years old had one or more Developmental Disabilities. (16)

Note: For the NHIS study above, the Centers for Disease Control and Prevention (CDC) and the National Center for Health Statistics (NCHS) conduct multistage probability surveys sampling U.S. Households, based on sample and in person interviews with a knowledgeable adult family member. (16) This data is mostly surveillance in scope and is not gathered at the time of birth, but possibly many years after the fact. This is one of the ways the CDC and NCHS collects data for research and policy making in the U.S. This type of surveillance gathering is subject to the accuracy of the recall of the parent. It would seem that it would be better to use a well established medical data collection system such as the U.S. Standard Certificate of Live Birth to avoid errors and to be able to review progress from birth.

Autism Spectrum Disorders (ASD)

In March 2014, the U.S. Department of Health and Human Services (DHHS) reported, “The latest figures from the Centers for Disease Control and Prevention (CDC) reaffirm that **autism is a critical public health issue that deeply impacts the lives of millions of Americans.**” (17)

The following chart shows the continuous rise in the prevalence of ASD from 2000-2010 as recorded by the CDC. (18)

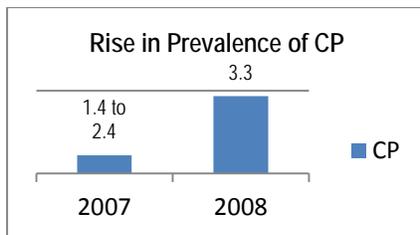


In the past, researchers ignored this continuous rise as a consequence of better pediatric identification or over diagnosing, however, when in March 2014 the CDC reported the 2008 to 2010 rise to 1 in 68 shown in this chart, which is nationally a 20% increase in ASD, **it is important to note that the CDC also recognized that they did not know all the factors that could contribute to such an increase in the incidence of Autism.** (19)

Cerebral Palsy (CP)

CP has been identified with similar risk factors, potential causes, and developmental delays as ASD, however, CP is also defined as a neuromuscular disorder: “characterized by non-progressive abnormalities in the developing brain that creates a cascade of neurologic, motor and postural deficits that may occur before, at, or after birth in the developing child. The site of damage may be the brain, spinal cord, peripheral nerves, neuromuscular junctions or the muscle itself.” (20)

The following shows the prevalence of CP given per 1,000 live births according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.



Despite medical advances, the statistics for Cerebral Palsy have risen slightly over 30 years. Although this is believed to be partially due to better neonatal care that can now save many more preterm children, in spite of the medical communities work on the importance of delivering a healthy baby, problems still do arise in childbirth and there are those injuries that are still considered potentially preventable. (21)

About half of all occurrences of CP are associated with underlying prenatal conditions such as intrauterine infection, perinatal anoxia, maternal metabolic disease, and birth events such as trauma or injury, infection, toxic exposure, and vascular problems. Although it was once thought CP was caused by perinatal hypoxia, it is

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believed hypoxia is a possible cause in less than 10 percent of children with CP. Estimating from the above prevalence rate there are 14190 children born each year with CP; 1419 CP cases a year are from hypoxia. (21)

It is important to note however, that the CDC admits that in half of all CP cases, no underlying health problem can be identified, and the CDC, recognizing there are unknown causes, has included CP in the research pursuits along with ASD in the 2014 Autism CARES Act. (22)

Developmental Disabilities are increasing yearly despite medical advances. The children with Developmental Disabilities, as well as, future children of this crisis, need and deserve our attention to prevent these disabilities. We know that many Developmental Disabilities are from injury or an anomaly at birth, which damages or causes malformation of the infant's vulnerable developing brain, but despite medical advances the CDC does not know the causes for the incredible rise in ASD and over half of all CP cases.

We applaud the CDC for including CP in this recent research to try to fill the gaps, however, how much of the new research will be based on actual prevention? The CDC's plans seem to be focused on surveillance, interventions, and treatments. We need to broaden and more effectively collect the data at birth, to prevent these disabilities from happening in the first place.

Developmental Disabilities are not curable and last an individual's entire lifetime.

Disability in childhood can result in lifelong health impacts. The child with disabilities can require more extensive health care needs, or have unmet needs for health or related services such as dental services, caregiver services, adaptive or wellness therapies or equipment.

Developmental Disabilities can affect several areas of child development and impair the child's performance and roles in society. They can experience health, social and environmental barriers to full participation in life events. Once interrupted the altered development of the child can affect everything they try to attain in their lifetime. Early identification and intervention, treatment, therapy, and special education work to assist the child to provide the best possible quality of life outcomes, however, disability at its worst can result in being cast aside from work, family, and community.

American children with disabilities are least identifiable in a social group, stigmatized, looked upon as different, and socially cast aside in our society. "In this society of the "sick" (therapeutic state) there is no place for any of the hallmarks of a present or future adult identity; no place for politics, no place for work and sexuality, no place for choice between competing moralities. All political, legal, and ethical issues are transformed into questions of disease and health, deviance and normal adjustment, proper and improper management of the disability."... "Of all America's oppressed groups, only the disabled have been so fully disenfranchised in the name of health." (23)

Everyone has the right to life, liberty and the pursuit of happiness, except seemingly those citizens with disability, who are discriminated against because of disability.

On this basis alone Developmental Disabilities are devastating to individuals and their families, but let us look closer at the devastating cost of disability to our children and future children.

Developmental Disabilities are a great cost to our children, families and society; they are a critical public health issue that deeply impacts the lives of millions of Americans. (24)

Each year approximately 120,000 children are diagnosed with a lifelong Developmental Disability. The CDC has estimated the lifetime cost of care for each individual citizen with Intellectual Disability and CP is nearly \$1 million (in 2003 dollars), approximately one half that figure for those with Vision or Hearing Impairments and less for ASD. (Caregiver, family out-of-pocket, hospital outpatient, emergency department, and residential care for persons not living in households were excluded due to limited data). This means that each year a cost well over \$75 billion (in 2003 dollars) is added to our societal debt over the duration of their lifetime. (25)

The cost of lifelong disability is far greater when we consider all the costs, such as special education and

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medical services. "State and Federal education departments spend about 36 billion each year on special education programs for individuals with developmental disabilities who are 3-21 years old." (26)

In addition, there are not just economic costs, but costs of time, delayed learning, stress and health, loss of ability to work or live a fulfilling life, loss of talent, productivity and contribution to society by both child and family and even bureaucracy. These costs continue to grow and become more of a challenge for communities and health systems. As these systems fail to respond, for families, costs become devastating. (27)

In addition, we overlook the daily challenges which can sap child and family from contributing to life and our society. Birth injuries can cause lifelong neurologic damage affecting learning, speaking, coordination, balancing and walking. They can cause involuntary movement making it difficult to carry anything, handle anything, take notes, control the volume of one's voice, and many more daily difficulties. Beyond the physical and/or cognitive consequences are the DAILY cost of frustration, loneliness, a life of poverty, and loss of freedom, including freedom of choice.

Children with Developmental Disability are at risk for diminished health, quality of life and negative psychological and social impacts. (27) Loneliness can lead to depression, social injustice can lead to lack of self-esteem or aggression, and frustration can lead to emotional or behavioral difficulties. Children and families often isolate themselves to save themselves from social injustice which may only serve to heighten their challenge for social and emotional development.

The cost to family can become overwhelming and break down the family support system that is so crucial to the person with a disability. Families are also expected to shoulder some expense, both personal and financial. The family overwhelmed by difficulties and limitations, devotion of time and effort to provide care, often experience work loss, poor mental and physical health and negative social consequences. The family can become overburdened. At its worst, the family can dissolve leaving no support for the child with disability. (28)

Disability in childhood can result in devastating lifelong, social, emotional, psychological, vocational, and economic impacts. As we have shown the cost of disability is so great that it is quite simply fiscally irresponsible for our collective futures to ignore the needs for research for prevention.

It absolutely would be fiscally responsible to deal with these disabilities; to lessen the burden of future individuals, their families and our society by strengthening existing data systems to advance understanding of the causes of Developmental Disabilities to prevent them. (29)

What we do not know cannot be allowed to go on. The time to act is today!

In the last 30 years there appears to have been a shift in focus and effort away from the actual prevention at birth of Developmental Disabilities. Prevention at birth has been ignored in legislation, policy and research, medicine and most of all, data collection which appears to have hindered efforts to find causes.

Legislation

- **Beginning in 1989**, some states administered programs to collect, analyze and disseminate information about adverse neonatal outcomes, birth defects, Developmental Disabilities and other severe disabilities in children from birth to age 6. These Birth and Developmental Outcome Monitoring Programs monitored birth defects but also, neuromotor conditions, developmental delay, cerebral palsy, cerebral hemorrhage, Central Nervous System outcomes of the head, musculoskeletal conditions and more. (30)

- **In 1991**, the article, "Disability in America: Toward a National Agenda for Prevention" by the National Academies Press, described the state of the U.S. developing an effective prevention program for disability. "Interfering with the development of effective prevention programs, however, is the lack of an effective public health surveillance network for **monitoring the incidence and prevalence of disability, including predisposing risk factors**. Without such a surveillance network, programs and policies intended to prevent disability will continue to be based on educated guesses rather than a solid data base that describes the sizable population of people that have either disabilities or a high risk of developing them. Furthermore, the fragmentation, gaps, and redundancies in the nation's disability-related programs—the focus of criticism in other quarters besides this report—will persist." (31)

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- **In 1999**, states replaced the Birth and Developmental Outcome Monitoring Program with the Birth Defect Prevention and Surveillance System. ASD, Cerebral Palsy and outcomes other than birth defects were redefined under Developmental Disabilities, many years earlier and not included in this new registry. (32)

Birth defect was defined as a structural deformation, disruption or dysplasia, or a genetic, inherited or biochemical disease. Physicians and pediatric clinics are required to report only birth defects in infants and children up to the age of 2 to the state's agency. Hospitals may, but are not required to report. (32)

With this shift in 1999, people with birth outcomes of Cerebral Palsy, Vision Impairment, Hearing Impairment, Autism Spectrum Disorder, Intellectual Disability, or Learning Disability defined by the term Developmental Disability, were now placed under different laws. Developmental Disabilities were no longer tracked, monitored or registered. **By changing the focus and only including birth defects in monitoring, how will we ever find the causes of Developmental Disabilities that we may prevent them? Not only do we not report Developmental Disabilities at birth, but there is no mandate to track Developmental Disabilities.**

- **By 2003 and 2004** birth defect registries were finally developed to collect the information on selected birth defects as described previously. In addition, electronic direct upload was requested from pilot sites and improvements in reporting were implemented. (33) Only certain birth defects are included in the list of those required by mandate and Developmental Disabilities are not part of the registry.

Although the state birth defect registries cannot use sources other than that monitored through their registries, they are allowed to use the U.S. Standard Certificate of Live Birth, as a comparative analysis to corroborate their data. (33) The current U.S. Standard Certificate of Live Birth collects information on birth "anomalies" and "conditions of the newborn," using checkboxes that lump choices together.

- Would it not be better if the U.S. Standard Certificate actually stated which birth anomaly or condition of the newborn, if known, instead of using vague terms, checkboxes that lump several choices together? This would help to better identify and corroborate both birth defects and birth injury.
- It is possible in our current day to use medical record automation which has the ability to recognize keywords to identify anomalies, procedures, conditions etc. by spelling them out and the American Obstetrics Association has been working to implement a standard terminology for all conditions and procedures of birth.

Currently research is focused on finding whether Autism may in some instances link cause with a person's genetic makeup. Likewise research is also finding that potentially 14 percent of CP instances may be caused by genetic mutations. (34) Birth defects often lead to developmental delays. The lines between birth defect and developmental disability may be blurring. Why shouldn't we monitor Developmental Disabilities at the time of birth for these reasons?

- In the 2014 Autism CARES Act the CDC will be pursue to identify research participants in 2 year olds to prove that screening children with Autism earlier would be more effective for treatment. Would it not be better to monitor abnormal neonatal outcomes from birth through 2 years old to get a more reliable data source of birth through diagnoses of disability and through the lifetime for long term side effects? (35)

Developmental Disability is defined in legislation for the purpose of granting services for disability, and no longer monitored for the purpose of prevention. Revisions were made 30 years ago that affected the monitoring of neonatal outcomes from all disabilities to just birth defects. Prejudging or suppressing information rather than learning from the data is reminiscent of a dark age of medicine philosophy.

- If we had kept the monitoring program, we might know a great deal more about developmental disability for this quickly developing crisis that we are now facing.
- Not all states have birth defect registries, but if we had continued to monitor Developmental Disabilities too, would we have the stepping stone of data between the cause at birth and the effect of these disabilities?

What other road blocks do we face to link birth with later development?

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Policy and Research

As early as 1974 the NCHS reported that an interagency council should be created to coordinate and promote research for the **prevention of disability from both birth defects and birth injury**. The National Council on Disability was formed in 1978.

In 1984, the National Council on Disability within the Department of Education was transformed into an independent agency charged with reviewing all federal disability programs and policies. Under the NCD statutes, there are among other provisions: (36)

- To provide advice to the Director with respect to the policies and conduct of the National Institute on Disability and Rehabilitation Research, including ways to improve research concerning individuals with disabilities and the methods of collecting and disseminating findings of such research. (37)
- To provide advice regarding priorities for the activities of the Interagency Disability Coordinating Council and review the recommendations of such Council for legislative and administrative changes to ensure that such recommendations are consistent with the purposes of the Council to promote **the full integration, independence, and productivity of individuals with disabilities**. (37)

A purpose of prevention was replaced with the purpose of improving the effects of Developmental Disability.

In accordance with the Children's Health Act of 2000, the Interagency Autism Coordinating Committee (IACC), lead by the National Institutes of Health (NIH) at the U.S. Department of Health and Human Services a Federal advisory committee was formed to coordinate ASD related efforts across HHS, partner federal agencies and private stakeholder groups and advise the Secretary of HHS on issues related to ASD. (38) IACC facilitates **ASD research, screening, intervention, and education**. As part of this effort, the National Institutes of Health has invested in research to identify possible risk factors and effective therapies for people with ASDs. (39)

Unfortunately, in 2014 the U.S.GAB released this report based on 2008 to 2012 on Federal Autism Activities: Funding and Coordination Efforts which found there was 84% or 1,018 projects – had the potential to be duplicative because the projects were categorized to the same strategic plan objectives or research or areas of research and that the IACC had little coordination between research. "Education, HHS and NSF do not show that they review research projects to ensure that they are not unnecessarily duplicative."(40)

Why are there so many projects that have the same objectives and duplication? The focus of prevention funding was changed in 1984 to focus on the effects of birth injury under the definition of Developmental Disabilities. **The prevention report changed from asking for the prevention of birth injury, the cause, to preventing the effect, Developmental Disabilities.**

We have no longer sought to find the cause of birth injury disability. We agree that efforts should be given for research for early diagnosis, early intervention, rehabilitation, speech, occupational and physical therapies, and special education for the child with the disability and the family. Prevention has come to mean dealing with the consequences of birth injury, not causes.

Although early diagnosis, intervention and developmental therapies are extremely important to alleviate the devastating effects of developmental disability and to improve lives, we have **lost focus to prevent Developmental Disability from happening in the first place.**

Here is an example of the research being done. National Institutes of Health (NIH) launched the Autism Centers of Excellence (ACE) program in 2007. This research again is focused on interventions, treatments, and brain development. "Data from the ACEs and other NIH funded ASD research is expected to be shared with researchers across the U.S. and around the world through the NIH National Database for Autism Research, maximizing the use of the data to accelerate ASD research. (41) This is a terrific effort for repository of research, and it is mostly focused on possible genetic causes and brain activity. Prevention must be the goal, and tracking data at birth is essential.

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The NICHD has overseen the Neonatal Research Network, a program to research neonatal medicine. This center's research database registers children born very premature and very low weight with various clinics. This information is descriptive of the baby's background, perinatal and neonatal experience. The research is done for the betterment of neonatal medicine so not focused on causes. This research should be commended as it follows outcomes of medical procedures for at least 18 months of the child's life. (42)

Just as discrimination laws took congressional action to change, it will take federal action to lead on funding research and technical advances in medical recording for the purpose of prevention. The medical community's interest in treating and caring for patients has an obvious financial benefit to their industry. The medical community does not have the economic interest in investing in research of birth anomalies or injury or obstetric procedures or the long term effects.

It is much more fiscally important for our society for our representatives in legislature to focus on prevention, to support data collection of birth and development and research needed to look long term effects to reduce costs.

Medical Community

Has there been any research on the long term effects on the child of medicines given to the mother during labor and delivery? There was a large increase in elective obstetric procedures in the 1990's when Autism began to increase. Are possible causes of Autism being overlooked?

1. Insurance will only cover so much care and those without insurance may not get the prenatal care to deliver their baby to term. Doctors and hospitals are under constraints from insurance companies for what is expected for normal prenatal care and delivery. There are questions on the birth certificate as to the source of insurance. Do we know the effect of insurance prescribed care versus best practices of medicine?

2. The 2005 report by the National Vital Statistics stated that the rate for the stimulation of labor increased 59% between 1989 and 1997. Doctors and parents scheduled induced labor or cesarean delivery for convenience rather than medical necessity. This increased several risk factors of delivery for Developmental Disabilities, induction of labor, cesarean delivery and preterm birth/low birth weight. Recent pressure from federal insurance policies and hospitals has begun to limit this practice. (43)

3. What do we know about the medicines used for inducing labor and controlling pain during labor? A woman can be very careful to not use any of the common Teratogens such as over the counter drugs such as aspirin, etc. but when she enters the hospital to deliver her baby she may well be bombarded by some of the most powerful medicines. Where is the research on the long term effects of the medications for inducing labor or delivery pain relief?

There does not appear to be research on the long term effects of medications. Without data collection we cannot support research needed and take the data of birth and development to look at the long term effects to reduce the costs. We need research attention on the long term effects of obstetric procedures and medications given and taken in childbirth!

Data Collection

We collect data on birth defects, but we no longer mandate data from the time of birth for those with other types of birth anomalies that may be important in identifying the cause of Developmental Disability. We do not mandate data from the time of birth or from the time when children are diagnosed with a developmental delay. If they enter public education at some point, there will be monitoring of a development delay.

There are various agencies collecting data including the CDC, but this data is not mandated and the data collection efforts have been largely through parent surveys rather than data collected at birth.

The U.S Standard Certificate of Live Birth and medical records do take data at the time of birth on birth anomalies and injury that may develop into life-long disability. The U.S. Standard Certificate of Live Birth is a multi-purpose document: a record of the vital event of birth, legal proof for the individual that birth occurred and "provides medical information to serve the needs of public health programs and health research." (44)

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After a baby is born alive, data is collected by doctors, nurses or other attendants at birth and hospital staff or other attendants record it on the U.S. Standard Certificate of Live Birth and it is signed by the attendant of birth. "It contains the names of the parents, their education and race, medical and health information about the pregnancy and the delivery, and also information on the newborn." (45)

This certificate is then sent to the individual state Office of Vital Statistics. (The state then issues a separate and brief form in a Birth Certificate to the individual.) Each state department of health, the U.S. Department of Health and Human Services, the CDC and the National Center for Health Statistics use the information provided on the U.S. Standard Certificate of Live Birth to collect and analyze data at birth for health statistics and research. (45)

As a data collection tool, the birth certificate is posed to give a great deal of information without duplicating other data collection programs, as it is also necessary for the function of determining citizenship.

The following is an example of data collection and how data collection could be improved.

A history of recording birth injury on the U.S. Standard Certificate of Live Birth is as follows below.

- **In the 1968 revision of the U.S. Standard Certificate of Live Birth** the following items were added "congenital malformations or anomalies of child" and "birth injuries to child" (46)
- **In the 1978** revision of the U.S. Standard Certificate of Live Birth, "Birth injuries to child" entry was removed from the items "because it was underreported." (47)
- **In 1985** the National Research Council and the Institute of Medicine released the landmark report "Injury in America," which identified injury as the leading cause of death and disability among children and young adults and, indeed, the principal public health problem facing America. Although this report covers all injuries to children, it also covers injury from the neonatal period of the lives of children. (48)
- **In 1989** revision of the Standard, "Congenital malformations or anomalies of child is replaced with just anomalies of child with checkboxes, more items are added "medical risk factors, "complications of labor and /or delivery, obstetric procedures, method of delivery, abnormal conditions of the newborn and congenital anomalies of child. For each of these topics there are multiple choice of subtopics, some grouped in multiples with each check box. "Abnormal conditions of the newborn" was incorporated with checkboxes.
- **On the 2003 Revision of the U.S. Standard Certificate of Live Birth, the birth certificate in use today,** under "abnormal conditions of the newborn," this revision limited reporting of birth injuries to: "significant birth injury (skeletal fracture), peripheral nerve injury, and/or soft tissue/solid organ hemorrhage which requires intervention." Birth Injury is included on the Fetal Death Certificate. The birth certificate does include: "risk factors in this pregnancy, infections present and or treated during this pregnancy, obstetric procedures, onset of labor, characteristics of labor and deliver, method of delivery, maternal morbidity, and abnormal conditions of the newborn, congenital anomalies of the newborn,

It is fairly clear that "birth injuries to the child" in 1968 was in time replaced in 1989 and 2003 with "abnormal conditions of the newborn." This crafting of language is of course to lessen responsibility on the doctor and we understand the consequences of such language, however, it is also clear that birth injury appears to not be getting much attention for improving the outcomes of obstetric practices for the unborn child.

1. Although each revision of the birth certificate emphasizes an expression of getting a clearer picture of the newborn, there is still a limitation of choices. These topics are main categories that include more checkboxes and a box is included for "none of the above." There is no write in available for "other" on any of these items.
2. A "significant birth injury" is under the heading an "abnormal condition of the newborn." Medical science wants to blame the newborn for their injuries?

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3. As we do not know the causes of Developmental Disabilities, we should be taking the data of birth injury, however insignificant, especially to the brain.

It is apparent injuries of the newborn still occur, as we do record birth injury on the death certificate. Reasons for reporting birth injury in the case of death would seem even more important for the child in life, yet there is only reporting of "significant" birth injury on the live certificate. This seems very subjective, when any injury to the brain may eventually turn out to be significant. Reporting of all birth injuries should be mandatory as some of the consequences of birth injuries are not diagnosed immediately after birth; perhaps not for several years.

In the 2006 AHRQ Statistical Brief, the number of potentially avoidable injuries to newborns (broken collarbone, an infection, or a head injury) in the U.S. were reported at 1.6 per 1,000 live births, (there were 4.3 million live births that year so 6880 births.) The brief was interested in advocating for the highest quality care for all patients in the U.S. and brought injuries forward for the purpose of preventing them. (49) It does not necessarily follow that these injuries will result in development disability, but there is no way to know unless we take the data.

The brief reported injuries to newborns was more common in newborn males than females. Whites experienced slightly higher rates than other races. The rate of injury to the newborn was 33 percent higher in the most remote locations of the country as compared to large metropolitan locations. The Northeast had 24-32 percent higher than those in other regions of the country. There were no significant differences in the rate of newborn injury between the wealthiest and poorest communities. (49) Although valuable how much can we infer from this research that has significance in finding the causes of Developmental Disabilities?

Research cannot experiment on mothers and babies; we must take the data at birth. If we take the data, we can decide, what is important or not. If data is not collected any statements regarding cause of disability is opinion or guess and not research based science.

The prevalence spikes for Autism have happened quickly and continue to grow each year. We must give our utmost attention now to research for the causes of Developmental Disability!

It is time for legislators, researchers, and members of the medical community to take leadership, have the discipline and due diligence and look at all that one is doing and evaluate to see if one can prevent what has happened. When something goes wrong, we should be looking at what one might have done to cause the train wreck, but data collection is focused at looking at all the other risk factors, yet not taking enough statistics of the actual birth conditions.

We need to begin today to more adequately research the causes of these disabilities and we need to more effectively collect the data from birth for that research.

Could road blocks to collecting data at birth and recent trends in birthing be placing newborns at risk from finding that which could be identified and may be potentially preventable?

We agree with the CDC that as a society, we cannot find causes, until we are effectively collecting data before, during, or after birth to identify causes or risk factors of Developmental Disabilities.

We must ask ourselves, are we doing everything we can do to provide the data of birth for research, are we doing the research to find the cause? Where is the data of birth injury? Where is the data to determine the cause?

Where do we collect data; how and what data is collected?

Other than the U.S. Standard Certificate of Live Birth and its accompanying parent survey and medical records there is no data collected at birth.

Other entities gather disability data, but no other data is collected at birth, except for the mandatory reporting of birth defects. Other birth anomalies are not included in this mandatory reporting. Other surveys include:

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- National Center for Health Statistics which conducts the yearly National Health Interview Survey (NHIS)
- International Center for the Disabled (ICD) survey, household disability statistics
- National Council on Disability survey, usually household disability statistics
- Survey of Income and Program Participation (SIPP) (50)

The CDC collects data for their research from two main research studies in the U.S. and projects their findings for statistics, however, these are based on parent or responsible adult answering questions about birth. **The CDC acknowledges that they are the only research being conducted on developmental disability.**

- The CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network is the only collaborative network to track the number and characteristics of children with ASD in multiple communities in the U.S. The ADDM Network is able to look at not only how many children have ASD, but which groups more likely to be identified and at what age they are likely to be diagnosed. (51)
- The CDC's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) is an ongoing and systematic monitoring of prevalence of selected Developmental Disabilities who reside in Atlanta. (51)
- Most other projects are on early detection and collaboration between providers and families. (51)

The CDC carries out other research for Developmental Disabilities, but these are done after birth and after diagnosis and rely on adult memory of birth rather than data collected at birth. The important Autism and Cerebral Palsy research by the CDC is based upon surveys requested of a responsible adult. Information on developmental disability is collected in surveys in which the focus is not on prevention, but a surveillance network of disability. Although the CDC reports these are detailed surveys, surveillance questions would include such items as what insurance was used or the education of the parents, which is also asked on the certificate of live birth. (51)

In 2013, the National Institutes of Health invested approximately \$186 million in research on ASD. No. 3 out of 4 objectives read: "identifying potential risk factors that may be linked to the cause(s) of ASD." The other 3 objectives were about early intervention and treatments. (51)

With the recent passage of the 2014 Autism CARES Act, more data collection for research will be required; however, existing CDC programs following these disabilities will continue to take prevalence statistics and appear to have no plan to increase or collect data at birth. (52)

"With this new round of funding, the CDC will invest over \$20 million over four years to enhance tracking at eight sites and launch two new sites in its Autism and Developmental Disabilities Monitoring Network (ADDM). All ten sites will track the number of school-aged children receiving autism services. Six sites will also track autism among preschoolers. Autism can be reliably diagnosed by age 2, however, the average age of diagnosis in the United States remained stalled at 4.5 years, as of last year's CDC estimate." (53)

The "National Autism Monitoring Network will look for advances in early diagnosis, with special attention to new criteria for diagnosis and will conduct research aimed at better understanding why prevalence is increased." (53)

Much of what CDC collects is also collected similarly by the department of education; more complete prevalence statistics are already available as the department of education collects extensive data on autism by year, age, and state. It is redundant to collect more prevalence statistics duplicating other government collected data. We understand we may never be able to collect all the data, but for the abnormal birth, the lack of comprehensive data collected at birth is marginalizing human life by failing to concentrate on data collection resources for prevention.

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There is a great need to broaden the scope of data collected on the U.S. Standard Certificate of Live Birth in accordance with medical research to find causes and identify ways to prevent Developmental Disabilities.

Do we collect the important data at birth necessary to address the cause and effect and therefore the prevention of lifelong disability?

Is data about wealth, insurance, education, enough to explain the environment of the newborn when we are asking about the health environment of the newborn?

Do we know what medications were used for mother and baby before, during and after birth? Do we know if the mother took over the counter medication or supplements? Has research concentrated on the long-term effects on the child of drugs given to the mother during labor and delivery?

Can we quantify and understand the impact of birth complications and birth injuries to be able to reduce adverse events and achieve higher quality of care?

Although medical science does acknowledge a complex mix of risk factors prevalent in the research of Developmental Disabilities, the CDC cannot identify all the causes. The fact is there are many ways that the developing brain may be subject to: stress, infection, endures trauma or injury before, during, and after birth to cause the abnormal formation or injury of the brain and we are not collecting reliable data on these.

The following are **risk factors** that are recognized in both Autism and Cerebral Palsy (54)

- Preterm and very preterm delivery - 11.7% or 463,163 children born in 2011 (55) "It is well- established that early birth can affect the developing brain." (56) "As the cause of labor still remains elusive, the exact cause of preterm birth is also unsolved. In fact, the cause of 50% of preterm births is never determined." (57)
- Low and very low birth weight 8.1% and 1.4% of children born in 2011 in the U.S. respectively. (58)
- Multiple birth
- Cesarean delivery - increased 60% from 1996-2009 reaching 32.9%, 32.7% in 2013. (59)
- Breech presentation
- In vitro fertilization or other Assisted Reproductive Technologies
- Brain injury
- Environmental factors

Much current research on Autism devotes funding and work to congenital causes and gene changes. These causes to brain abnormal formation or brain injury may not be preventable, but a recent study by Stanford University School of Medicine of twins showed that genes only account for 38% risk and 62% risk are explained by environmental factors. (60) With so many environmental variables, we need to broaden the scope of data to more adequately collect data at birth, to assist in identifying these factors.

These are a list of some of the most common Teratogens identified to have an adverse effect on the developing fetus and child: Alcohol, Aspirin, Cortisone, Caffeine, Tetracycline, Tobacco, Tranquilizers, and chemicals – Methyl Mercury, pesticides, and lead. (61)

These obviously have been researched, yet do we know the long term effects to the fetus. Recent research has looked at Tylenol as contributing to ADHD. In another study an environmental stressor, severe cold weather was determined to be a cause for more incidence of Autism.

Parents are told to avoid over the counter medications, alcohol, and smoking and yet, when the mother goes to the hospital to have her baby, she could be granted the most powerful of labor inducing drugs and pain relieving epidurals, which may be causing more havoc on the developing fetus. (62)(63) How often are these administered for convenience and not medical necessity? This data should be collected on the standard certificate and children monitored to determine the long term effects of these obstetric medications used during childbirth.

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For many Developmental Disabilities, causes are unknown. We find ourselves guessing at the possibility of causes from new trends in child birth. Advances in medicine need more research to determine their effect on the developing brains of our children.

These possible causes such as assistive reproductive technology, induced labor and cesarean delivery scheduled for convenience or scheduling delivery prematurely, obstetric practices or procedures, medications used during pregnancy and childbirth, environmental factors, interventions used in childbirth, and changes in care for mother and child before, during and after birth may be determined to be identified as preventable.

Birth certificates, hospital records or medical records should state the circumstances at birth. If we kept more adequate records on this information prior and during the gestation through birth process and after birth, we may be able to better determine cause and effect without guessing. With the rapid changes in medicine and approaches to birth, we need to collect the data at birth. If data is not collected, then statements regarding cause of disability are based on opinions or guesses and not research based in science.

Please see below about how we should broaden the data collected at birth on the certificate of live birth.

Research has a challenge to link cause with effect.

Without data collection and without a system that checks back on that data when a diagnosis is realized, how are we ever going to connect cause and effect? How are medical science and our sense of humanity ever going to learn how to prevent ever increasing number of children with disabilities?

The effect of brain trauma or injury at birth and resulting developmental delays and disabilities, such as Autism, ADHD, visual problems, cerebral palsy and learning disabilities may not become apparent or are generally NOT diagnosed until a child is older, possibly 2, 3, 4, 6, 8 years of age or older, therefore the circumstances of birth can easily be overlooked. Are the records of birth still available when the child is diagnosed? Most research projects begin with the evidence of disability in the older child and must look back to the past to the circumstances of birth relying on parents' and doctors' memories. (64)

This gap between the entire pregnancy and birth and cause of brain development interruption and the consequential effect of developmental delay and disability becomes the difficulty to address the cause and effect of lifelong Developmental Disabilities in a meaningful way.

The CDC is working with the Danish national public health data systems on the causes of Autism. Denmark links more than 200 long-term disease registries with birth data collection systems with conditions of the newborn and then monitors them over a period of time. (65)

In addition to mandating essential information on birth certificates, linking or tracking birth and education records or monitoring disabilities could provide the tool in determining the causes of Developmental Disabilities.

This Prevention Report is a call for the USDHHS, NCHS and CDC to establish a new review panel including medical professionals and researchers to develop an updated revision of the current U.S. Standard Certificate of Live Birth (last revised 2003) to more effectively collect vital, statistical data from before, during and after birth for a more scientific approach for the purpose of preventing disability.

DHHS, CDC, and NCHS, have done a remarkable job with past data from the standard certificate of live birth, however, the last review of the standard was 13 years ago. (66) The U.S. Standard Certificate has been reviewed and updated every 10-15 years for the past century. (67) As advances in medicine and birthing standards change at more rapid rate, 10 years is a long time to wait for change. The data collected on the standard is vague and not in sync with the rapid advances in medicine for today's research needs.

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This Prevention Report is a call to revise the current U.S. Standard Certificate of Live Birth (last revised 2003) to be more specific in documentation and for a more scientific approach to collect vital statistical data from before, during and after birth of each citizen born in the U.S.

We agree that the standard should include that which is necessary for legal, research, statistical or public health programs and be reasonable in completeness and accuracy, however the current standard could be far more specific and detailed.

In addition to what is on the current form, for example, we suggest consideration of broadening data to include:

-ALL neurological dysfunctions, not only "serious dysfunctions or seizure."

-ALL birth injuries, not only "significant" injuries.

-ALL medicines, anesthetics, analgesics and stimulants used, including specific doses.

Name and dosage of stimulants used for induction or augmentation of labor.

Name or type of analgesics or anesthetics used in addition to those currently required.

-A place to clarify Apgar score.

-A place to add specific information about presentation at birth or if other abnormal conditions are present to list them in addition to the 'check the box' choices.

With ongoing advances in automation of record keeping, medical and data collection agencies at the local, state, and federal level will be better able to be much more efficient in updating to a revised standard. (68)

This Prevention Report is a call for legislation that each state accepts this new minimum standard certificate and to update medical and data agencies for recording the new standard for uniform, reliable data collection.

Since the last update of the U.S. Standard Certificate of Live Birth in 2003, almost all 50 states have adopted the standard.

Last year, however, only 44 states had adopted the standard by 2013. By 2015, it is expected that data for all reporting areas will be based on the 2003 U.S. standard certificate providing national data for these and many other important demographic and medical and health items. (69).

This standard is our only hope of collecting data at birth and we are waiting 10 years for states to ratify the standard. There is an epidemic and we are waiting for 10 years!

The NCHS does not "mandate" that States collect all the data on the standard certificate, "NCHS strongly encourages the States to conform to the standards as closely as possible. Even small deviations from the Standard can have critical implications for both the states' and national files because of the loss of data, quality, and comparability." (70)

13 years ago it was a lot of work to automate the record keeping of hospitals and state and federal agencies to collect the data. With ongoing advances in automation of record keeping, medical and data collection agencies at the local, state and federal level will be able to be much more efficient in updating to a revised standard. The standard could be more comprehensive, ask more detailed questions because of computer automation, and the essential information could be mandated.

The NCHS, the National Association for Public Health Statistics and Information Systems (NAPHSIS), and individual state and jurisdictional vital statistics partners are working to improve the quality of birth data by developing national standards for the automatic transfer of medical and health birth certificate data directly from hospital electronic records to state electronic birth registration systems. The NCHS is also working to improve data timeliness and quality via increased standardization for 57 vital records reporting areas (states and provinces of US) to federal vital statistics. (71)

Data collected on the U.S. Standard Certificate of Live Birth will benefit government, individual, and medical, obstetric and pediatric research efforts.

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This Prevention Report is a call for education and training for hospitals, doctors, nurses, and other attendants of birth to lead the call for prevention to observe and protect the unborn; to review and educate all attendants of birth, to advise parents for healthy prenatal care, to measure quality of care outcomes and to identify and prohibit known obstetric techniques that put children at risk of disability. This is also a call to continue educating medical staff the importance to record the data on the revised standard certificate of live birth for research in the prevention of Developmental Disability.

Quality of Care

Are ASD or CP possibly caused by injury, medications used, obstetric procedures or complications from preterm birth or very low weight in childbirth? With the large increase in elective obstetric procedures and the use of stimulant, analgesics and anesthetics at birth through the 1990's, could there be a connection?

"Adequate research on the benefits and risks of medical practices used during childbirth evaluate the quality of medical care provided during childbirth and the timing of scheduled cesarean sections." (72)

As early as 1927, "The preeminence of trauma among the causes of intracranial hemorrhage in infants is now almost universally accepted. Obviously any condition which increases the stress which the fetal head sustains in its passage through the birth canal will increase the chances of injury. Contracted or malformed pelvis, rigid soft parts, precipitate or prolonged labor, abnormal presentation, high forceps deliveries, breech extraction, or over-large fetal heads are all common factors which predispose to birth injury." (73) The nervous system has many factors of safety and compensation, but the means of actual repair is individual. Although adults have a chance at cure of neurologic injuries, children whose brains are developing, not fully formed brains, have little chance of using these compensation factors. (73)

In the last decades there has also been a large increase in elective obstetric procedures which also use stimulants, analgesics and anesthetics. Is there a connection? What are the long term effects of these procedures and medications?

"Since 1979, the American College of Obstetricians and Gynecologists has recommended against deliveries or induced labor before 39 weeks unless there is a medical indication, such as the mother's high blood pressure or diabetes or signs that the fetus may be in distress." "Babies born before 39 weeks are more likely to have feeding and breathing problems and infections that may result in admissions to neonatal intensive-care unitsthe elective deliveries may cause developmental problems." (74) Although there have been developments in neonatal clinical practice to limit neurological damage in the case of premature birth such as in cooling the brain to reduce damage and better ways to ventilate the baby to ensure oxygen is getting to the brain, in this research study of people born between 1973 and 1985, they found there are more incidences of psychiatric disorders in those who are born prematurely than full term birth, attributed to "disrupted development" of the brain. (75)

Shorter pregnancies from 1980 to 2011 had been blamed on the use of induction of labor and cesarean delivery prior to full term. This demonstrated greater risks to infants compared with those delivered later in pregnancy. Induction of labor had increased nearly every year since 1990, but had declined in 2011 and 2012.

"Doctors have been warned for decades about the dangers of delivering babies early without medical reasons, but the practice remained stubbornly persistent. Now, with pressure on doctors and hospitals from the federal government, private and public insurers and patient advocacy groups, the rate of elective deliveries before 39 weeks is dropping significantly 17% in 2010, 14% in 2011, and 11.2% in 2012, according the latest hospital survey from The Leapfrog Group, a coalition of some of the nation's largest corporations that buy health benefits for their employees. This represents however, only about one third of all American health facilities." (76)

The U.S. DHHS Agency for Healthcare Research and Quality, in their June 2014 Future Research Needs: Evidence-based Reports Comparative Effectiveness Reviews, systematic reviews of existing research on the effectiveness, comparative effectiveness, and comparative harms of different health care interventions, are intended to provide relevant evidence to inform real-world health care decisions for patients, providers, and policymakers. An important part of these reviews is to not only synthesize the evidence, but also to identify the gaps in evidence that limited the ability to answer the systematic review questions. The following is a research study that they are intending for 2014: No. 22: Future Research Needs for Strategies To Reduce Cesarean Birth in Low-Risk Women. (77)

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Federally funded research has not concentrated on the long-term effects on the fetus of drugs given to the mother during labor and delivery.

The GAO recognizes that long term follow up studies are also important. Perinatal interventions may dramatically alter later growth and development. (In the newborn) There is also an increased recognition of the potential disconnect between perinatal outcomes and long-term effects. The administration of oxygen and postnatal steroids are prime examples of interventions that may have positive effects, but negative long term effects.

Parts of the brain are fairly well developed at the time of birth but other parts are not, particularly the cerebellum. Introduction of medicines during this period of rapid development even for one administration can kill or cause aberrations in cells. Cells in the cerebellum will need to move to their final position, linking up with other cells. "Both the rate of cell death and the patterns of migration of cells in the cerebellum have been shown to be very sensitive to the introduction of toxic substances. (78)

"Medications can potentially permanently disrupt the normal link up of the baby's brain cells; this alters the biochemical markers that guide the cells into their proper places. The cells connect, but not correctly. Not only is this a problem for the baby, but damage can be transmitted from generation to generation. This is all the more reason to be careful with using medications in pregnancy and labour (labor)." (78)

Does the FDA have the opportunity to observe long-term effects of obstetric drugs on infants until drugs are marketed and used extensively, and can they ensure that FDA knows about all adverse reactions to marketed drugs? (79)

Have we done everything we can to educate all attendants at birth of the safest obstetric practices, identified those techniques that put children at risk, or educated the public on the risks and benefits of these procedures and medications offered in pregnancy and delivery?

Although medical advances have worked to assist the preterm and very low weight baby, much could be done to avoid these risk factors. This is a call for more quality care assurance measures in the use of birth intervention, more education in obstetric techniques to avoid injuries, and a TEAM approach.

Importance of Collecting Data

After the revision in 2003 of the U.S. Standard Certificate of Live Birth, the NCHS hoped to be able to report the new statistics that had been implemented. Analyzing the integrity of the information collected, they came to several conclusions including that several items were underreported. To correct these problems, improved efforts were made to train hospital staff to record the data from birth.

Although a 2011 NCHS report states that underreporting of health conditions is considered a primary limitation of both medical and birth certificate data, they state, "There is the potential for high-quality national data for many birth certificate items that appeared underreported." (80)

In an NCHS Data brief of 2014 it was noted that that induction of labor is underreported on the birth certificate. The sensitivity of this issue is substantial from 14% to over 50% in validity studies. (81)

How can we determine any conclusion about induction of labor or that matter any sensitive issue on the birth certificate? Hospitals and doctors must be educated in the importance of recording procedures used at birth for the research for prevention.

In their 2013 report, NCHS is confident because they reported several ways that they were implementing a plan to improve the quality of birth data. E-learning training for hospital staff, promoting universal use of the standard definitions and instructions to complete the birth certificate health information, and a joint committee was reported identifying data quality issues and promoting hospital understanding of the importance and use of birth data.

The American College of Obstetricians and Gynecologists has been developing a national standardization of obstetric clinical data definitions for electronic health records and birth certificates to be incorporated for the birth certificate. (82)

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With these programs already in place and the improved automation of birth data and vital statistic records mentioned above, we can address a far more comprehensive data collection. We can collect the actual conditions of birth. New manuals of course will be required for hospitals, clinics, attendants at birth and staff to be able to update to the new standard.

If we don't collect the information, how will we ever know if ASD and other Developmental Disabilities are related to birth injury and/or medications?

This Prevention Report is a call for more funding of education and assistance programs for students and future parents of healthy prenatal care, risk factors of disability and the importance of their role in protecting the unborn. A far greater effort has to be made at prevention!

Medical science does acknowledge the cause of some Developmental Disabilities. For instance it is thought that fetal alcohol syndrome is caused by the mother drinking alcohol during pregnancy. We as a society know now, how to prevent this syndrome, but how seriously do birth mothers take these warnings? Have we really done our best to educate people to the effects of alcohol on the unborn or for that matter any of the other known substances that cause disability?

No one wants to scare people from having children, but with knowledge comes informed parents. Public school health education places great emphasis on not shaking a baby as this can cause injury, and they teach to live a healthy lifestyle to have a healthy baby.

Very important is actual healthy prenatal care. It is documented that healthy baby programs assist parents to carry babies to full term and that these programs do reduce Developmental Disabilities. (83)

Parents should be educated and informed on current risks and benefits of obstetric procedures and medications so they can make informed decisions in conjunction with health care professionals about elective procedures during routine childbirth, such as elective induction of labor or use of anesthetics.

It is mandated to wear a seat belt to drive a car, yet how informed are we on the procedures used to bring a baby safely into this world? Require by law that doctors make information available to all expectant parents months prior to delivery to enable parents to ask questions and have a voice in any health decisions.

This is a call for "Educational efforts for public awareness of the benefits and importance of preventing or favorably timing pregnancies that could or may be high-risk, seeking prenatal care early during pregnancy, and seeking periodic well-baby care for infants. Improve access to health care for low income women, including health education, family planning, prenatal and well baby care, labor and delivery services and newborn intensive care." (84)

Summary

Developmental disability is increasing. Each year 75 to 120 billion dollars is transferred to the future debt because our generation refuses to collect the data and pass it to the next generation. (85) (86) Mandate to research and to remove duplicated research services. History of science is filled with instances of steadfast practices, later proven to be harmful. Pregnancy medications and obstetric practices are full of instances where doctors and pharmaceutical companies thought that a medication or procedure was safe only to find out that they were creating great harm.

This is a call for better measures and greater coordination of data and data sources across agencies and levels of government to strengthen existing data systems to advance understanding of the causes of childhood disabilities and guide the formulation of more strategic, responsive and effective policies, data collection, research, programs, and interventions for the prevention of Developmental Disabilities. (87)

Prevention of disability without first scientifically, accurately and efficiently collecting data will be impossible for this and unknown future lifetimes.

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