

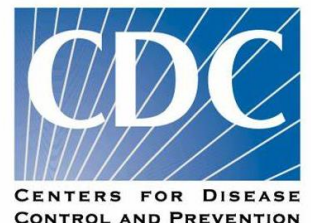


DIVISION OF HUMAN DEVELOPMENT AND DISABILITY

STRATEGIC PLAN

National Center on Birth Defects and Developmental Disabilities

FY2024 - FY2028



LETTER FROM DR. KARYL RATTAY, DHDD DIRECTOR

Dear Colleagues,

I am excited to present our completed FY2024-2028 Strategic Plan for the Division of Human Development and Disability (DHDD). I am looking forward to this refreshed strategic direction that will help guide the important work and collaborative opportunities of DHDD during the next five years. And I am exhilarated by our new vision: People with disabilities and developmental concerns achieve their optimal health and well-being.

Since joining CDC over a year ago, I have been continuously impressed and inspired by our team's devotion and commitment to improve the health and well-being of the communities we serve. Through data, evidence-informed strategies, and partnerships, DHDD is truly making a difference in promoting positive health and well-being outcomes, reducing health disparities and inequities, and enhancing access to health and community services.

This success would not be possible without the perspectives shared by the populations we serve, as well as critical support from our CDC colleagues and key partners, who play a role in making DHDD's mission and vision a reality. Through close collaboration with teams across CDC, DHDD has achieved significant milestones while propelling the broader Agency to a more inclusive and innovative future. We also have immense gratitude for our partners, who continue to strengthen and extend the supports, services, and interventions we offer, creating an impact we could not achieve alone. Collectively, we have forged invaluable relationships and advanced shared goals in a wider range of human development and disability areas, for which I am extremely grateful.

I am so proud of the DHDD team and the impact our work has had for the communities we serve. DHDD staff have embodied our Division's values and overcome challenges to accomplish meaningful work, all with enthusiastic attitudes and uplifting spirits. I am excited to move forward together with our goals to provide high-quality, timely, and actionable data; support the awareness and implementation of impactful interventions inclusive of policy, systems, and environmental (PSE) changes; strengthen systems and supports across the lifespan and at critical transition periods; and enhance coalitions, strategic partnerships, and technical assistance.

Thank you for all that you do,



Karyl Rattay, MD, MS, FAAP

Director, Division of Human Development and Disabilities
National Center on Birth Defects and Developmental Disabilities
U.S. Centers for Disease Control and Prevention





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DOCUMENT SUMMARY

From September 2023 through January 2024, the Centers for Disease Control and Prevention's (CDC) Division of Human Development and Disability (DHDD) **undertook a collaborative and inclusive strategic planning process** to define its goals and strategies for the next five years (FY2024-2028).

This document details the DHDD Strategic Plan, including a background summary of the organizational priorities and structure of DHDD, an outline of the Strategic Plan's development and future management, details to help define and clarify the intention of the Plan, and the Division's Vision, Mission, Values, Goals, and Strategies for the next five years.

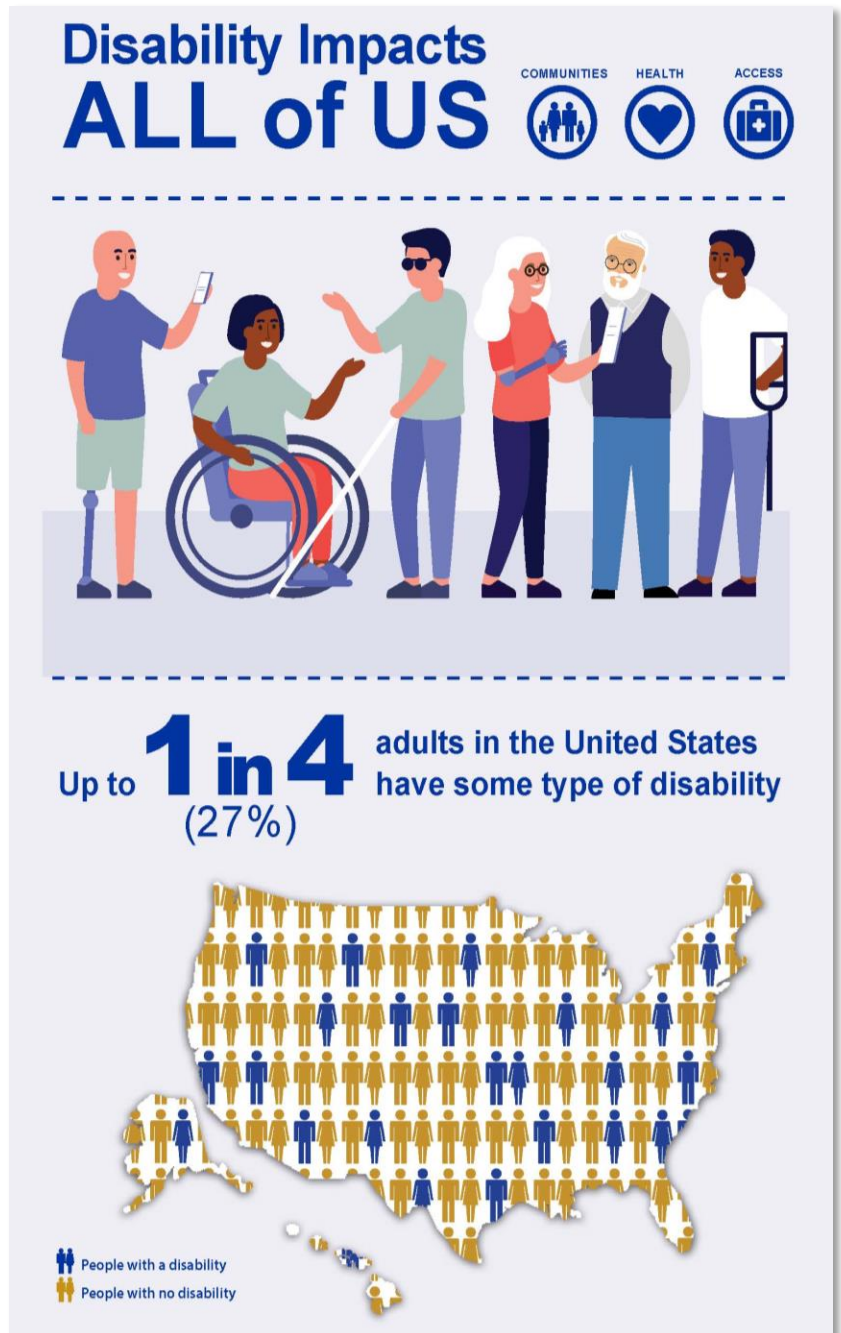
The Strategic Plan will be used to ensure alignment of DHDD priorities, articulate the Division's scope of work and unique role, effectively communicate and collaborate with CDC colleagues, partners and communities and **position DHDD to have the greatest impact** in advancing health and well-being for people with disabilities and developmental concerns.



BACKGROUND

DHDD serves a diverse population including people with intellectual and developmental disabilities, mobility limitations, neurodevelopmental disorders, and other functional limitations, as well as children whose families have concerns about them meeting developmental milestones.

Disabilities and developmental concerns are a common part of life and impact almost every person, either directly or through others in their life. However, **people with disabilities and developmental concerns can often experience unique challenges achieving their optimal health.** Intellectual and developmental disabilities, lifelong disabilities, or acquired disabilities can be associated with an additional level of complexity when navigating other medical needs and conditions. People with any disability type more commonly have arthritis, depression, diabetes, obesity, high blood pressure, and heart disease. **These challenges contribute to increased healthcare costs and barriers to fully participate in society.**



[Disability Impacts All of Us graphic](#) via DHDD website

In fact, a 2021 survey showed that in the previous year, 20.3% of adults with any disability type could not see a doctor due to cost, compared to 7.3% of people without disabilities.¹ **Many of these health and social impacts, however, can be prevented or reduced through access to high-quality healthcare,** community services, public health programs, and inclusive environments for all people.

¹ Centers for Disease Control and Prevention. (2023, May 3). Disability and Health Data System (DHDS). <https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html>

BACKGROUND

Disability inclusion creates opportunities for people with disabilities and developmental concerns to live their fullest lives and experience increased participation in socially expected life roles and activities. Disability inclusion is integral for ensuring people with disabilities and developmental concerns have the same opportunities to be well, active, and involved in all aspects of life.

Public health approaches can help address systemic disability issues, mitigating the barriers faced by people with disabilities and developmental concerns, and promoting disability inclusion. For example, addressing gaps in disability and health data — including inconsistencies in disability indicators and data elements across different data collection mechanisms and limited questions on functional difficulties — could improve disability representation and ensure data are relevant, timely, and actionable.

This Strategic Plan, and its subsequent implementation, **seeks to build on recent successes in the public health and disability landscape**, data and programmatic insights, and lessons learned from DHDD's work and public health responses, such as COVID-19, to inform the future direction of the Division.



ABOUT DHDD

As part of CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD), **DHDD plays an important role as a public health leader** that works to promote optimal health and well-being and reduce disparities for people with disabilities and developmental concerns (see Figure 1). DHDD's public health approach includes the application of data, surveillance, epidemiology, impactful interventions, partnerships, communications, and policy to advance its goals.

DHDD is funded by Congress to advance a variety of specific areas in human development and disability, including attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), cerebral palsy (CP), early hearing detection and intervention (EHDI), fragile X syndrome (FXS), outcomes among people with mobility or intellectual disabilities, and Tourette syndrome (TS).

DHDD maintains several key programs that advance the Division's work:

- ADHD and Tourette syndrome surveillance and health promotion
- Autism and Developmental Disabilities Monitoring (ADDM) Network
- Disability and Health Data System (DHDS)
- Early Hearing Detection and Intervention (EHDI)
- Fragile X Online Registry With Accessible Research Database – Multiple Assessments for Research Characterization (FORWARD-MARCH) studies
- Learn the Signs. Act Early (LTSAE)
- National Center on Health, Physical Activity and Disability (NCHPAD)
- Special Olympics Healthy Athletes and healthy Communities program
- State Disability and Health Programs
- Study to Explore Early Development (SEED)

Figure 1: Lifespan Graphic

DHDD's work, goals, and objectives strive to provide equity to people with disabilities throughout their lives by leading inclusive programs, surveillance, and research in the key milestone areas listed below

COMMITTED TO IMPACT ACROSS THE LIFESPAN

Childhood

Readiness and Well-being



Emphasizing the well-being of infants and young children through early identification, monitoring, and intervention

Young Adult

Successful Transitions

PUBLIC HEALTH STRATEGY

Supporting adolescents and young adults at critical transition periods in health care, education, housing, and other aspects of life

Adults with Disabilities

Optimized Health



Promoting health and well-being of adults with disabilities through data collection and programs for public health action

ABOUT DHDD

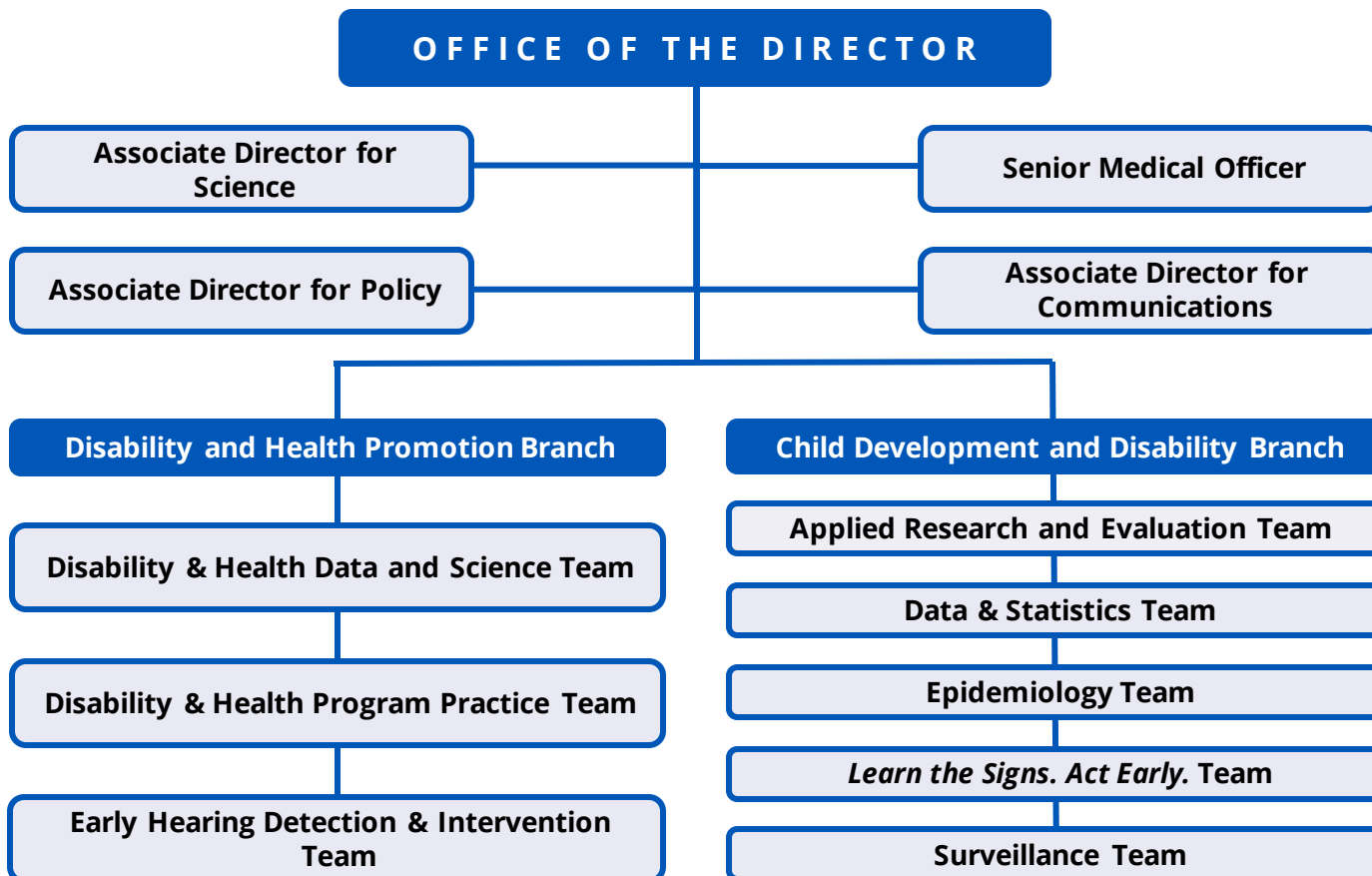
DHDD's organizational structure includes the Office of the Director (OD) and two branches: the Disability and Health Promotion Branch and the Child Development and Disability Branch (see Figure 2).

DHDD is made up of public health experts specializing in epidemiology, data, applied science, program implementation, health equity, health education and communication, and other relevant disciplines.

The Division could not accomplish its mission to promote optimal health and well-being for people with disabilities and developmental concerns without partners, including non-governmental, Local, State, and Federal Agencies, and other professional and academic organizations. References to "partners" throughout this Strategic Plan are inclusive of these organizations. DHDD is also part of a broader CDC ecosystem, working to progress disability inclusion; collaborative action between DHDD and other CDC Centers, Institutes, and Offices is essential for providing unified guidance, implementing comprehensive and multi-faceted public health solutions, and being at the forefront of human development and disability issues. **These collaborations are core to DHDD's work and were instrumental in developing its new strategic direction.**

Figure 2: DHDD Organizational Chart

DHDD staff is composed of public health experts that sit within the Division's OD and two branches.



STRATEGIC PLAN DEVELOPMENT AND MANAGEMENT

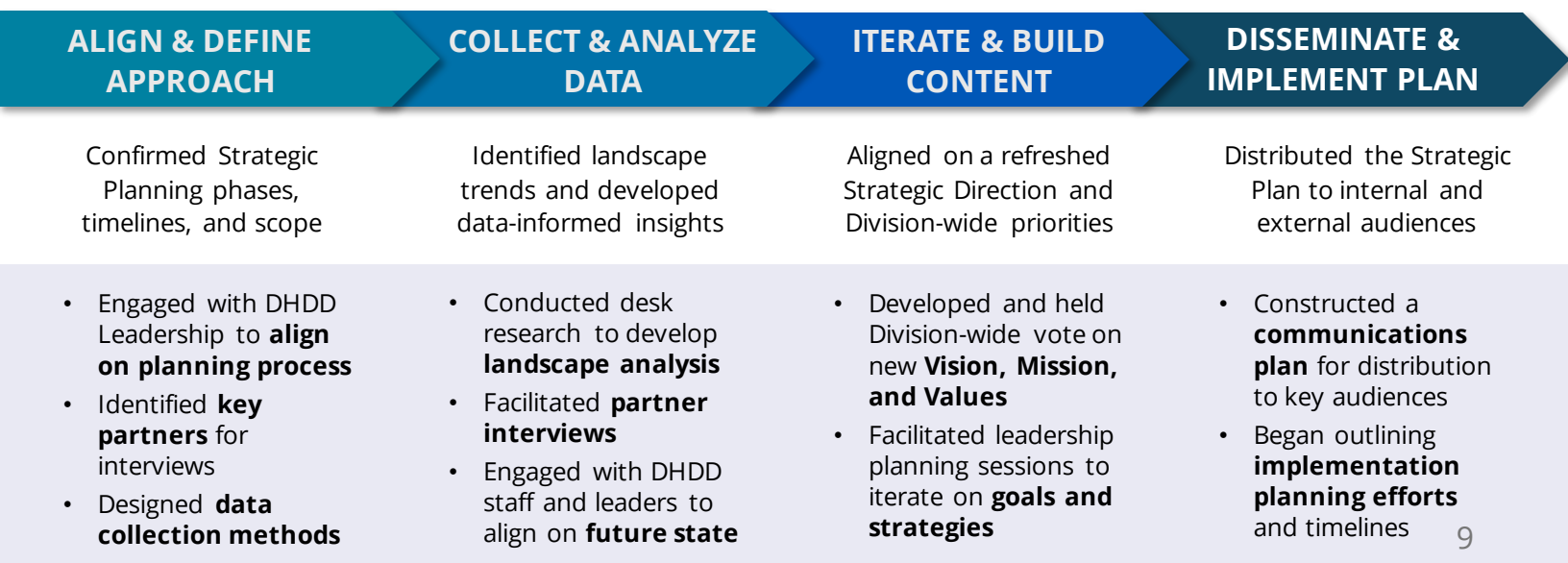
Changes in the public health landscape, including the COVID-19 Public Health Emergency, made it worthwhile for DHDD to refresh its Strategic Plan. The DHDD Strategic Plan was developed over a 5-month planning process and builds on the Division’s foundation of work while exercising flexibility to address evolving public health priorities and have the greatest impact. The Strategic Plan is a **guidepost for the Division’s core operations and priorities for the next 5 years (FY2024-2028)**.

The Strategic Plan was developed through a **collaborative process** that included an analysis of the human development and disability landscape, engagement with internal colleagues and partners external to CDC, and regular feedback from NCBDDD leadership and DHDD leadership and staff. The sequential steps taken to build the Strategic Plan are outlined in Figure 3, with frequent iteration to apply new information and continuously engage NCBDDD and DHDD colleagues to ensure alignment and buy-in.



Figure 3: Development Approach

DHDD deployed a four-phased approach to develop the Strategic Plan.



STRATEGIC PLAN DEVELOPMENT AND MANAGEMENT

The DHDD Strategic Plan is a **living document that can evolve over the next 5 years to meet changing public health priorities and needs.** To ensure that the Strategic Plan continues to provide impactful guidance, the DHDD Office of the Director Leadership Team, in collaboration with Division leaders, will regularly convene to verify alignment across CDC, NCBDDD and Division priorities with funding and resource capacities, and broader trends across the human development and disability landscape. Implementation of this plan will involve outlining specific activities that can be executed for each Strategy and supporting DHDD's tracking of progress. CDC colleagues and partners will continue to provide input to inform components of the Strategic Plan and make updates based on completed actions, new ideas, and shifts in broader strategic priorities.

The Strategic Plan is a **publicly available document intended to be shared with several different audiences.**



STRATEGIC PLAN APPLICATION

This Strategic Plan can serve a variety of purposes, including:



ROLE DEFINITION

Clearly define DHDD's role that complements its partners and outlines the Division's unique value within CDC



COMMUNICATION AND COLLABORATION

Articulate DHDD's areas of focus and expertise and where there are collaboration and partnership opportunities to advance the Division's mission and vision



PROJECT MANAGEMENT

Guide internal DHDD discussions to monitor progress, track the advancement of Strategic Plan components, and adjust organizational direction, as needed



GROWTH AREA IDENTIFICATION

Provide a blueprint for the organizational areas to expand and/or enhance based on available resources



STRATEGIC DIRECTION

Move DHDD forward to have the greatest impact for the communities it serves



STRATEGIC PLAN APPLICATION

Key terminologies included throughout the Strategic Plan are defined below.



ACCESSIBILITY

Design, construction, development, and maintenance of facilities, information and communication technology, programs, and services so that all people, including people with disabilities and developmental concerns, can fully and independently use them. Accessibility includes the provision of accommodations and modifications to ensure equal access to employment and participation in activities for people with disabilities and developmental concerns, the reduction or elimination of physical and attitudinal barriers to equitable opportunities, a commitment to ensuring that people with disabilities and developmental concerns can independently access every outward-facing and internal activity or electronic space, and the pursuit of best practices such as universal design.



DEVELOPMENTAL CONCERNS

Concerns about how a child plays, learns, speaks, acts, or moves and any other physical, learning, language, or behavior areas at a young age.



DISABILITY

Any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).



EQUITY

The state in which everyone has a fair and just opportunity to attain their highest levels of health. Achieving this requires focused and ongoing societal efforts to address historical and contemporary injustices; overcome economic, social, and other obstacles to health and healthcare; and eliminate preventable health disparities.



INTERSECTIONALITY

The complex, cumulative way in which the effects of multiple forms of discrimination (such as race, ethnicity, gender, sexual orientation, gender identity, class, and disability) combine, overlap, or intersect, especially in the experiences of marginalized individuals or groups.

STRATEGIC PLAN GLOSSARY



INTERVENTIONS

Programs, practices, or policies that can identify the health statuses or behavioral risk factors for disabilities and developmental concerns, improve access to services, provide education and support to individuals, encourage health-related behaviors or attitudes, and improve the health and well-being of people with disabilities and developmental concerns.



POLICY, SYSTEMS, AND ENVIRONMENTAL (PSE) FACTORS

Legal, institutional, physical, and other socioeconomic factors that can create sustainable, lasting change and make healthy choices practical and available to all residents. Policy, systems, and environmental approaches seek to go beyond programming and into the systems that create the structures in which we work, live, and play.



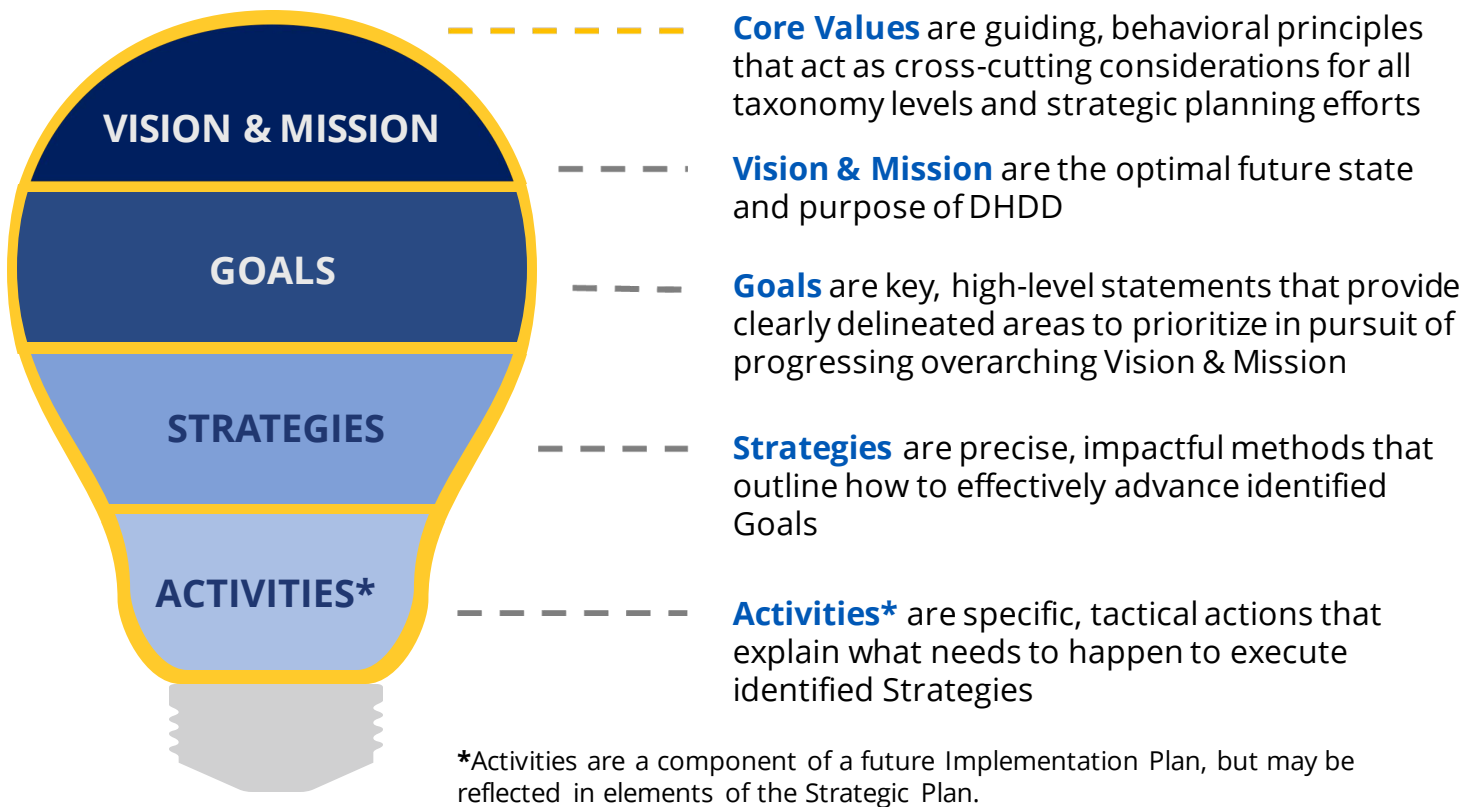
SERVICES

Supports offered to people in a variety of areas, including healthcare, childcare, housing, transportation, education, and others.

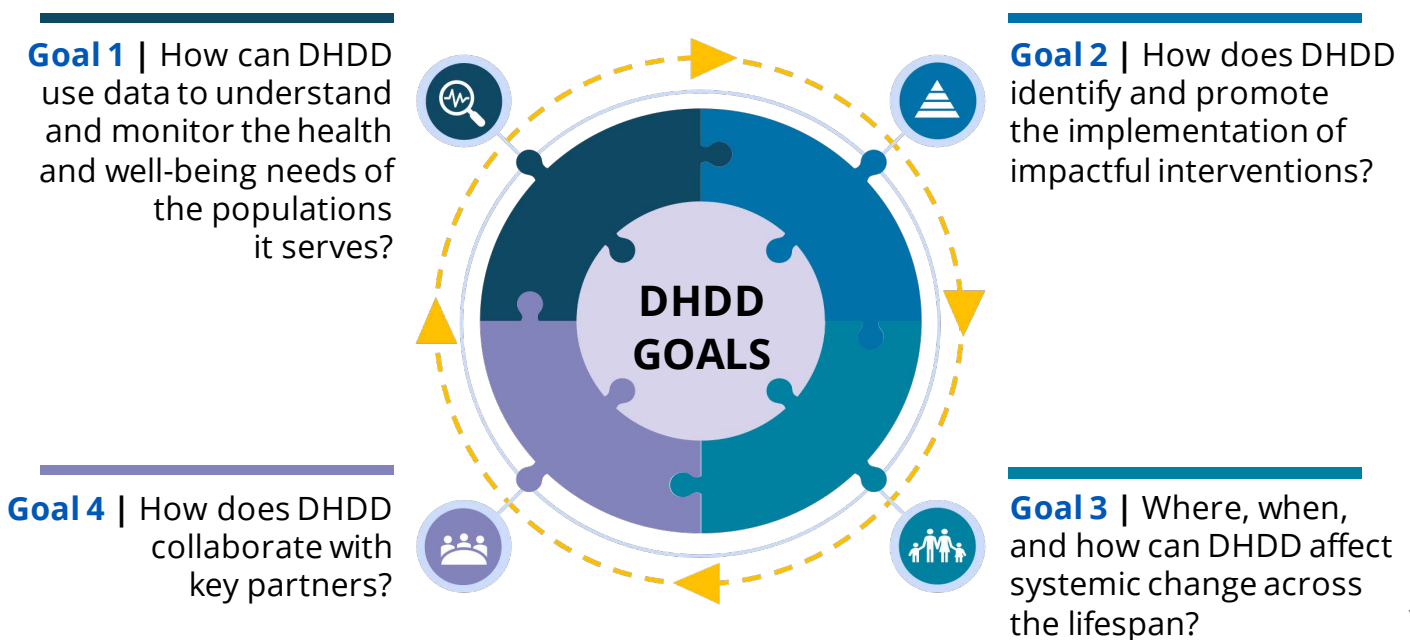


STRATEGIC PLAN OVERVIEW

The below taxonomy provides the structural components of the Strategic Plan and its subsequent implementation for DHDD moving forward.



Strategic Plan components are all connected to one another. In particular, the below visual illustrates how **DHDD's Goals are distinct yet intercorrelated**, with each one addressing a different aspect of the Division's work and aspirations and key questions that drive the Strategies under each Goal.



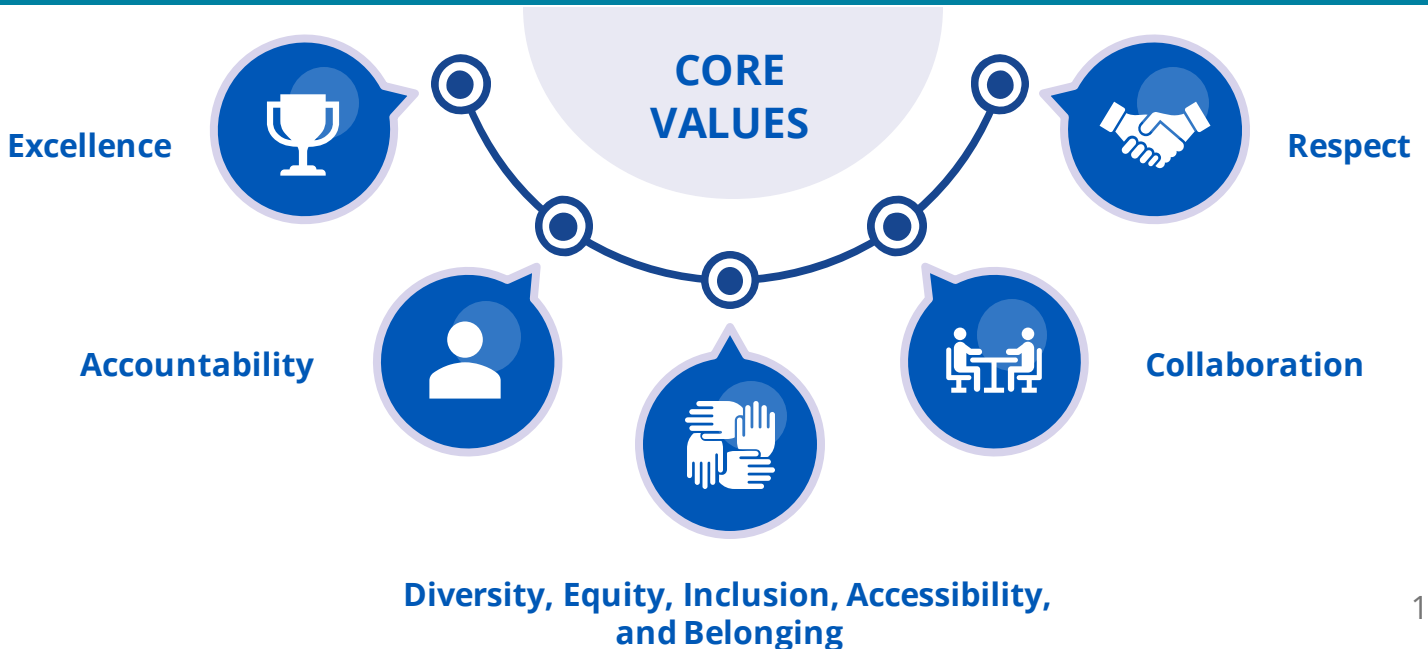
STRATEGIC PLAN OVERVIEW

VISION

People with disabilities and developmental concerns achieve their **optimal health and well-being**

MISSION

DHDD leads **public health efforts** for people with disabilities and developmental concerns across the lifespan through **data**, evidence-informed **strategies**, and **partnerships**



STRATEGIC PLAN: GOAL 1

Provide high-quality, timely, and actionable data

DHDD aims to expand data, surveillance, and epidemiology efforts to understand, monitor, and promote the health and well-being of people with disabilities and developmental concerns, which includes understanding inequities and intersectionality and ensuring consistency of terminology across public health data sets.

1.1

Strategy 1.1

Enhance population-based surveillance, epidemiology, and data systems across the lifespan

1.2

Strategy 1.2

Advance efforts to increase data integration and linkage

1.3

Strategy 1.3

Implement processes to accelerate the dissemination and accessibility of high-quality, evidence-based data

1.4

Strategy 1.4

Support communities to have and use data for action and impact for people with disabilities and developmental concerns

1.5

Strategy 1.5

Use data to identify intersecting health inequities experienced by people with disabilities and developmental concerns

DATA SPOTLIGHT - ADDM NETWORK

DHDD regularly collects and analyzes disability and health data to better understand their populations served and identify trends and disparities.

As the largest ongoing ASD tracking system in the country, **the ADDM Network collects data on the prevalence and characteristics of children with ASD and other developmental disabilities** in multiple communities in the United States. It analyzes how many children have ASD, which groups are more likely to be identified with ASD, and at what age they are likely to be diagnosed, helping to inform focused and impactful initiatives, policies, and research that support children and families living with ASD.



STRATEGIC PLAN: GOAL 2

Support the awareness and implementation of impactful interventions inclusive of PSE changes

DHDD aims to identify, promote, and support strategies and interventions that create meaningful and impactful changes in the lives of people with disabilities and developmental concerns.

2.1

Strategy 2.1

Enhance understanding of PSE factors on health and well-being outcomes across interventions

2.2

Strategy 2.2

Increase internal and external capacity to promote PSE approaches and integrate into interventions

2.3

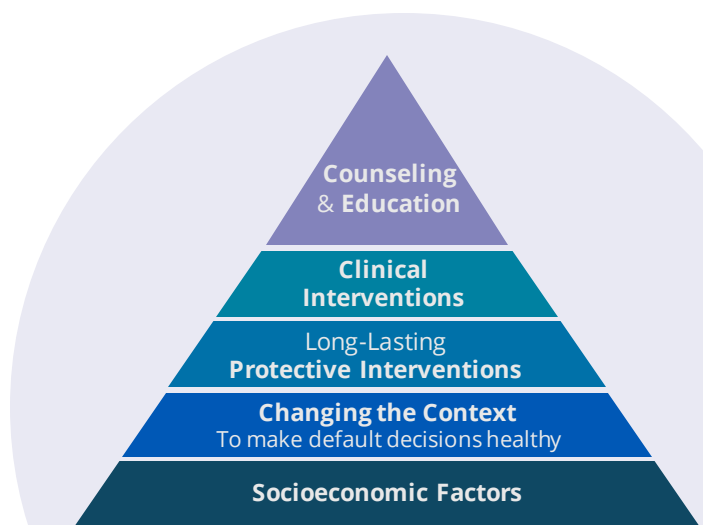
Strategy 2.3

Evaluate and encourage wide adoption of interventions that promote equity for people with disabilities and developmental concerns

PSE SPOTLIGHT - CHANGLAB SOLUTIONS COLLABORATION

CDC's **Health Impact Pyramid** (right) shows PSE factors that can affect health.

DHDD is working with ChangeLab Solutions to analyze current policies and create tools to increase the use of evidence in policymaking aimed at improving the health of children with disabilities. This collaboration has developed key resources that inform decision-making (e.g., factsheets, legal epidemiology databases) and led to insights on economic security policies, such as Supplemental Security Income and Earned Income Tax Credits, housing and school disciplinary policies, and healthcare policies related to telehealth and Medicaid prior authorization, all of which support or differentially impact children with disabilities (particularly ADHD and TS).



STRATEGIC PLAN: GOAL 3

Strengthen systems and support across the lifespan and at critical transition periods

DHDD aims to use data, tools, and resources to promote consistent, high-quality services and environments across the lifespan – especially at critical transition periods – for people with disabilities and developmental concerns and the people who support them.

3.1

Strategy 3.1

Advance early identification of developmental concerns and disabilities

3.2

Strategy 3.2

Use data to better understand healthcare and service receipt and access at critical transition periods

3.3

Strategy 3.3

Increase the awareness and promote implementation of effective strategies to address gaps in services and supports and barriers to access across the lifespan

3.4

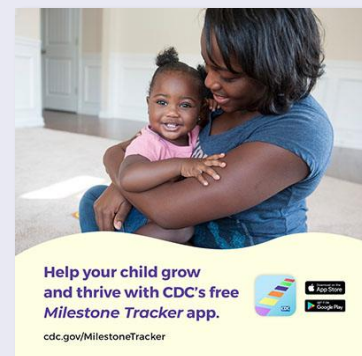
Strategy 3.4

Promote the systemic advancement of disability inclusion

INTERVENTION SPOTLIGHT - LTSAE & SEED FOLLOW-UP

DHDD's Learn the Signs. Act Early. (LTSAE) program **provides tools to track childhood development and supplies evidence-backed guidance** when concerns arise. Its resources are used nationwide to help families and early childhood providers identify disabilities and developmental conditions early so that children can receive needed services to help them thrive.

DHDD's Study to Explore Early Development (SEED) Follow-Up research **collects longitudinal data on participants to monitor developmental trajectories** from childhood to adolescence and young adulthood. SEED Follow-Up assesses the developmental impacts of healthcare utilization, educational attainment and needs, and family and social environments, as well as how development compares between participants with ASD, those with other developmental disabilities, and the general population.



[LTSAE Milestones in Action graphic](#)

STRATEGIC PLAN: GOAL 4

Enhance coalitions, strategic partnerships, and technical assistance

DHDD aims to strategically identify, collaborate with, and leverage key partners as well as provide technical assistance to promote optimal health and well-being for people with disabilities and developmental concerns.

4.1

Strategy 4.1

Create an aligned partnership vision with shared measures

4.2

Strategy 4.2

Increase collaboration and information-sharing to advance collective priorities

4.3

Strategy 4.3

Strengthen technical assistance across partners that support people with disabilities and developmental concerns

4.4

Strategy 4.4

Maintain and enhance results-based engagement with diverse strategic partners

PARTNERSHIP SPOTLIGHT - EHDI JOINT LOGIC MODEL

DHDD's Early Hearing Detection and Intervention (EHDI) program collaborated with the Health Resources and Services Administration (HRSA) to develop a **Cross Agency EHDI Logic Model** between March-August 2023. Both CDC and HRSA fund state/jurisdictional programs to improve outcomes for deaf or hard of hearing children and their families – CDC's activities focus on data collection for program improvement while HRSA's activities support child and family access to services.

The logic model will be utilized over the next five years, serving as a dynamic tool and graphical representation of EHDI priorities across HRSA and CDC. This cross-agency collaboration has already facilitated several key outcomes that **enhance the effectiveness and impact of EHDI programs** (see right).

— IMPACT —

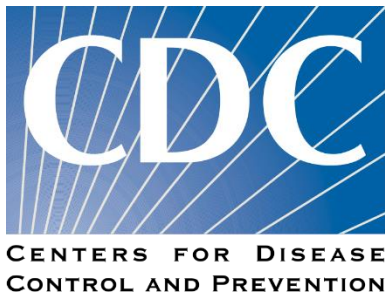
- Ensuring that HRSA and CDC EHDI programs **align with legislative requirements**
- Facilitating the coordination of activities and **avoiding duplication** of efforts
- Ensuring the alignment of **quality measures** to assess progress
- Facilitating the **exchange of best practices**, leading to continuous improvement and more effective strategies over time

APPENDIX

As aforementioned, this Strategic Plan was built through a collaborative process with engagement from colleagues within and partners external to CDC. We would like to extend a special thank you to our DHDD leadership and staff who devoted their time and energy to ensure this Plan was reflective of our broader values, commitments, and goals. We also greatly appreciate other members of the CDC team who provided valuable input throughout this process and strengthened our strategic alignment with the Agency. Lastly, thanks to our partners who embarked on this journey with us by contributing their unique insights and continuously elevating our work (listed below). We look forward to implementing this Strategic Plan to advance our collective priorities and are excited for the opportunities to continue meaningful collaboration. **Once again, thank you for your continuous support and determination to improve the health and well-being of people with disabilities and developmental concerns!**

DHDD PARTNERS

- Administration for Community Living (ACL)
- American Academy of Pediatrics (AAP)
- American Association on Health and Disability (AAHD)
- American Speech-Language-Hearing Association (ASHA)
- Association of Maternal and Child Health Programs (AMCHP)
- Association of State and Territorial Health Officials (ASTHO)
- Association of University Centers on Disabilities (AUCD)
- Autism Science Foundation (ASF)
- Autism Society
- Autism Speaks
- Autistic Self Advocacy Network (ASAN)
- CDC Foundation
- CDC Office of Health Equity
- Cerebral Palsy Foundation
- Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)
- Department of Education (ED) Office of Special Education Programs
- Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB)
- National Association of County and City Health Officials (NACCHO)
- National Association of Councils on Development Disabilities (NACDD)
- National Center on Health, Physical Activity and Disability (NCHPAD)
- National Council on Disability (NCD)
- National Fragile X Foundation
- National Institutes of Health (NIH) National Institute of Child Health and Human Development (NICHD)
- Partnership for Inclusive Disaster Strategies
- Special Olympics
- Tourette Association of America (TAA)



To learn more about the DHDD, please visit our [website](#).