Task Force on Disability & Health

Final Report and Recommendations

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Alternative formats available upon request
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Statewide Disability and Health Task Force

Project Overview

In 2013, the Centers for Disease Control released its second report on Health Disparities and Inequalities, summarizing findings across a wide range of diseases, behavioral risk factors, environmental exposures, social determinants, and health-care access by sex, race and ethnicity, income, education, disability status, and other social characteristics. Health disparities among people with disabilities has been one of the most recent points of attention, as the data demonstrate significant differences between the general population and people with disabilities in chronic illnesses such as diabetes, cardio-vascular health, smoking, obesity and access to public health programs and health care. Despite the fact that Indiana was not selected for specific CDC disability and health program funding, we have taken on the challenge of addressing these health disparities with existing resources.

Phases I-II (September 2013 – December, 2013)

In response to this charge, the Indiana State Department of Health contracted with the Indiana Institute on Disability and Community to build a foundation of knowledge and stakeholder participation that could lead to improvements in health for people with disabilities. The contract began on September 1, 2013 with work conducted over the period of September – December. The initial goals of the project are identified below, followed by their respective outcomes:

Conduct a statewide chronic disease public health needs assessment related to persons with disabilities

- Provided a working draft of statewide health needs assessment of persons with disabilities on topics of 1) chronic disease prevention and control and 2) access to health care services affecting chronic disease prevention and control.
- Implemented a first iteration (soft launch) of a comprehensive online and mail survey that provided baseline information regarding health status, chronic disease and access to chronic disease-related services and programs, to be completed by adults with disabilities, family members of children and adults with disabilities and professionals/policy makers providing services, supports and advocacy for children and adults with disabilities in Indiana. Launched at the 2013 Indiana Governor's Conference for People with Disabilities, December, 2013.

Develop an assessment of data sources addressing chronic disease and prevention and control (including access to health care services) for persons with disabilities in Indiana

- Created a ten-page database (Excel) of existing public health databases providing, for each database:
  - Name of the database
  - Link to the agency source
  - Whether the database contains disability-specific information
  - How data was collected
  - Whether data includes specific disability categories
  - Description of the data
  - Additional information
Note: A review of the data sources provided a basis for project staff to make recommendations to ISDH regarding disability-specific questions for the upcoming Indiana BRFSS survey process.

- Created an online resource library with the following components:
  - Resources: miscellaneous – 31 files
  - Indiana Coalition plans – 9 files
  - ISDH publications on chronic disease – 15 files
  - Disability data and statistics – 15 files
  - Journal articles – 33 files

Conduct an assessment of state and local policies and programs addressing chronic disease prevention and control (including access to health care services) for persons with disabilities in Indiana

- Created a six-page general inventory of state and local programs addressing chronic disease prevention and control
- Created a four-page general inventory of Indiana health and disability programs
- Created a 31-page inventory of physical activity, nutrition, and arthritis programs and policies.

Identify and consolidate annotated contact information for key stakeholder groups that serve, come into contact with, or support children and adults with disabilities in Indiana

- Created a 19-page file list (Excel) of stakeholders and stakeholder organizations for potential inclusion in a statewide Task Force on Disability and Health.

Implications of Phase I-II: The first phases of the project provided a foundation of knowledge and a comprehensive list of stakeholder organizations that can be invited or expected to take leadership for addressing the health disparities experienced by people with disabilities in Indiana. This work paved the way for Phase III, the creation of a state advisory group and the development of a state plan.

Phase III
The contract for Phase III with the Indiana Institute on Disability and Community for work in 2014 included the following goals, here followed by outcomes.

The creation and organizational support of statewide health and disability Task Force

- Drawing from the Stakeholder list, project staff, with assistance from ISDH, recruited fifteen knowledgeable and experienced individuals to commit to monthly meetings and pre-meeting preparation for discussion of chronic illness and disability. Meetings were held at The ARC in the Collaborative Work Lab, a digital “think tank” that facilitates discussion and priority setting. Members were provided access to the comprehensive online resource files created in Phases I-II of the project. Meetings included both presentations from outside experts, discussion of readings and sharing of knowledge.

Statewide health improvement planning related to health of people with disabilities in Indiana

- The Task Force met monthly in three-hour meetings to systematically discuss diabetes, cardio-vascular disorders, cancer, obesity, and at the recommendation of the ISDH liaison, behavioral risk factors associated with chronic illness: physical
activity, nutrition, smoking, and environmental barriers to access to prevention, education, and care services.

- In August of 2014, the Task Force began a systematic review of its own discussions in order to establish a set of priorities, identifying the most important issues to address across all conditions and risk factors, along with potential action steps that can be taken through the leadership of engaged parties throughout Indiana.
- Two additional meetings were scheduled to distill a list of recommendations for a health improvement plan for Indiana. In November of 2014, the Task Force will review the final list and a set of briefs established for each issue, in preparation for the first public revelation of the report at the Indiana Governor’s Conference for People with Disabilities in December.

The overarching goal and specific recommendations the Task Force developed for each of the chronic diseases and risk factors addressed are included following this narrative.

Next Steps for 2015-2016

A major conclusion of the Phase III project is that the most effective and productive avenue to reducing health disparities among people with disabilities would be to tap the leadership and skills of organizations currently conducting public health programs, who do not adequately reach out to serve people with disabilities. This approach is seen as preferable to the development of a new system designed to serve the health needs of the sub-population itself.

Hence, during 2015-2016, said organizations throughout Indiana will be invited to participate in a statewide discussion of the Task Force recommendations, via a series of “talking tours” entitled Community Conversations. Organizations that can better serve people with disabilities, from both the health and disabilities fields, will be invited to discuss the practical implications of the recommendations and identify educational and technical assistance needs that might help the organizations perform and collaborate more effectively.

The information gathered in the Indiana “Community Conversations” will be utilized to develop a curriculum for the Pathways to Health Summit. The Summit will provide an opportunity for health educators, promoters, and providers throughout Indiana to become more familiar with the scope of the problem and actions that can be taken to address the problem through their local leadership. In addition, the Summit participants will be introduced to a new “Pathways to Health” compact that, it is hoped, will be signed by them near the conclusion of a Summer Summit on Disability and Health.

The Pathways to Health Compact signatories will become the nucleus of an ongoing statewide effort to address health disparities among people with disabilities and provide a national model for statewide health improvement for this population.

Alternative copies of this report are available upon request. See staff contact information on page 28.
IDENTIFIED BARRIERS

Task Force members catalogued a variety of known barriers that prevent people with disabilities from receiving education and services that foster healthy living and/or care and management of chronic diseases. They are summarized below:

1. People with disabilities and family members do not receive adequate information, education, and follow-up to make self-determined decisions about their health and wellness status.
2. People with disabilities do not always have easy access to weight loss, physical activity, and smoking cessation programs.
3. Generic community health and wellness programs do not always target or reach people with disabilities and their families.
4. Transportation is a major barrier to accessing treatment as well as health and wellness programs.
5. People in poverty situations often cannot afford health care maintenance (medications, follow-up visits) and healthy lifestyle activities (food choices, physical activities).
6. Staff of disability service providers who work with people with disabilities also need information and education about health risks and behaviors in order to model healthy lifestyles.
7. Language, print materials, websites, and medical equipment are not always provided in ways that are accessible and understandable to people of various disabilities.
8. There is a scarcity of data regarding the health status of people with disabilities at local and state levels.
9. Many communities do not have physical and accessible infrastructures to support healthy lifestyles and use of community health resources.
10. There is a lack of coordination and collaboration between disabilities programs and health and wellness programs that results in many current health and wellness programs not being well utilized by people with disabilities.
OVERARCHING GOALS
Reducing Health Disparities for People with Disabilities

GOAL: Individuals with disabilities will have the same access to health and wellness resources and can attain the same level of good health as all community members do.

- **Community and public health programs** will explicitly include children and adults with disabilities and their families as a target population in health promotion and treatment efforts.
- **Disability related organizations** in communities will collaborate in promoting and implementing health and wellness promotion activities.
- **Communities** will take on a policy of deliberate inclusion and targeting of people with disabilities similar to other minority groups in health promotion and chronic disease management and prevention efforts.

IMPLEMENTATION: Areas of potential collaboration include:

- **People with disabilities** will receive education so that they are empowered to make informed choices, exercise self-determination, and take personal responsibility for their wellness and health care.
- Outreach efforts of **health-related organizations and initiatives** will be expanded to be more inclusive of people with disabilities.
- **Disability service providers and organizations** will promote and implement health and wellness practices not only for their clients, but also for their staff and volunteers.
- **Health care providers and programs** will provide inclusive, accessible, and adapted communication methods, equipment, and educational materials.
- **Communities** will make needed environmental and infrastructure changes to become more livable and to improve the health of all residents.
- **Health and disability-related services** at state and local levels will gather, use, and share data about the health status of people with disabilities.
RECOMMENDATIONS AND POSSIBLE ACTIONS
TO ADDRESS CHRONIC DISEASES

The Indiana Department of Health convened a Task Force on Disability and Health for the purposes of making recommendations to alleviate health disparities related to chronic diseases. The Task Force considered four areas of focus: diabetes, cardiovascular disease, and cancer were the first identified and then obesity was added as a chronic disease.

DIABETES
Recommendations and Possible Action Steps

1. **Individuals, families, and caregivers are educated about the health issues related to diabetes risk factors, screenings, prevention, and management (pre-diabetes, Type II, Type I).**
   1.1 Individuals and families will be educated about the importance of asking their primary care provider to regularly monitor risk and health issues related to pre-diabetes.
   1.2 A cadre of life coaches that come from the target groups themselves will be developed; e.g. peer to peer training by and for people with disabilities.
   1.3 Individuals and families will have improved access to information about pre-diabetes screening.
   1.4 Diabetes education will be sustained over the life course, from youth to old age.
   1.5 Family caregivers will be targeted to receive education about diabetes prevention and management in order to provide support and improved access to care.
   1.6 People with disabilities will receive regular screenings at a level equivalent to those without disabilities.

2. **Disability Service Providers insure that clients under their care are receiving pre-diabetes prevention, testing, and education protocols by physicians and other health care providers.**

3. **Physicians and other health care providers apply diabetes risk factors, screening, prevention, and education protocols to people with disabilities.**
   3.1 Physicians and other health care providers will follow pre-diabetes testing standards and participate in community education efforts around pre-diabetes and diabetes.
   3.2 Children will be screened as part of Early and Periodic Screening (EPSDT).
   3.3 Adequately funded triage efforts will focus on pre-diabetes in adults and primary prevention among children and youth.
   3.4 Patients with intellectual disabilities will be offered the same standards of healthcare that apply for the general population.

4. **Community organizations, programs, and services will ensure that people with disabilities are included.**
   4.1 Food service establishments will provide training for personnel and consumer materials that provide and explain nutritional information in all formats for customers with disabilities.
5. Existing educational programs and materials for diabetes prevention and management are evaluated for literacy levels to ensure that they are accessible to a variety of people with a disability.
   5.1 Existing educational programs will be evaluated for literacy levels to ensure that they are accessible to a variety of people with a disability.
   5.2 Professionals and service providers will be provided with materials that accommodate a variety of disabilities.

6. Access to primary care is eased in order to facilitate diabetes prevention and management for people with disabilities – e.g., expanded number of appointment openings, longer appointments, more hours of operation, and sick visits/short notice openings.
   6.1 Primary care providers will have more capacity to serve patients with Medicaid
   6.2 Cost barriers to change at the provider level will be analyzed.

7. Disability organizations and service providers adopt diabetes education and outreach for their staff and their constituents.
   7.1 A coalition of disability organizations will be developed to take these recommendations and adopt them for their respective populations.
   7.2 Appropriate state agencies will be linked with disability organizations to coordinate the delivery of resources.
   7.3 Professionals and service providers will take ownership of the need to address diabetes prevention in their organizations
   7.4 12 statewide disability organizations will adopt diabetes education and outreach for their staff and their constituents.
   7.5 Cost barriers to change at the provider level will be analyzed.
   7.6 Disability Service Providers will insure that clients under their care are receiving pre-diabetes prevention, testing, and education protocols for physicians and other health care providers.

8. Long-term grants for diabetes prevention and management are developed and funded.
   8.1 New funding initiatives from any sector will emphasize sustainability and attempt to achieve longer range support for grantees.
   8.2 Every existing grant given by ISDH, FSSA, DCS (Child Services) will include a section that all grantees must address diabetes prevention within every grant regardless of its primary task.

9. Support training and expansion of certification programs such as the National Diabetes Prevention Program's (NDPP) lifestyle coaches.
   9.1 The National Diabetes Prevention Program (NDPP) will be linked to county and state parks and recreation departments and provides outreach for people with a disability.
   9.2 Training and expansion will be supported for certification programs for NDPP lifestyle coaches.
9.3 Individualized lifestyle coaches across Indiana will be supported to enhance their capacity to conduct diabetes prevention support.

9.4 Disability and advocacy organizations will offer NDPP training for Self-Advocates and staff.

10. Identify people with disabilities in state data collection protocols around diabetes.
   10.1 Children 0-18 will be included in data collection.

11. Local communities set aside funding to expand access recreation, exercise and community life opportunities that result in healthy outcomes related to diabetes.
   11.1 Safe sidewalks, bike routes, and park systems will be expanded.
   11.2 Environments will be created where moving more and eating better are simple choices.

12. A variety of accessible technologies around diabetes prevention and management are developed and/or promoted, and people with disabilities are supported to use them.
   12.1 A variety of smartphone applications will be identified and promoted; people are directed to the applications and applications are disability-friendly, affordable, and ubiquitous through social media marketing.
   12.2 The use of applications that connect one’s Community Health Worker to the patient's information, with appropriate controls over privacy will be enabled.
   12.3 Social marketing campaigns will be developed to promote use of disability-friendly phone-health applications.

13. Communities will have a variety of accessible transportation and mobility options for individuals and families so they can easily utilize community resources for prevention and management of diabetes (health care, food choices, recreation and education).

14. Individuals and families will be included in community programs and services to support healthy outcomes around diabetes.
   14.1 Organizers of community health fairs will expand outreach to people with disabilities.
   14.2 Communities will connect families, people with disabilities, and their support/advocacy organizations to elevate attention to diabetes as a critical health need.

15. Communities provide more access to fresh foods and vegetables for those in "food deserts."
   15.1 New funding will be located to support community planning and action to decrease the number of food deserts affecting people with disabilities.
CARDIOVASCULAR DISEASES
Recommendations and Possible Action Steps

1. Physicians and other health care providers expand access to screening, prevention, and education protocols to people with disabilities in order to reduce cardiovascular risk factors.

2. Disability service providers insure that clients under their care are receiving cardiovascular health prevention, screening, and education protocols by physicians and other health care providers.

3. Methods that address needs for communication adaptations are incorporated into cardiovascular prevention and treatment programs such as Sign Language interpreting, visual supports, simplified literacy level reading options.
   3.1 Methods such as visual supports, simplified literacy level reading options and augmentative communication systems will be incorporated to address needs for communication adaptations in cardiovascular prevention programs; i.e., healthy eating, physical activity, smoking cessation,
   3.2 There will be adequate numbers of Certified Sign Language Interpreters to provide access to education, information, and direct care for families and individuals.
   3.3 There will be increased access to resources for health care professionals to adapt their services and care; e.g., websites with information about how to better perform general health and cardiovascular screening in an individual with communication limitations.

4. Already existing health consortia/committees /task forces will promote better outreach regarding cardiovascular disease prevention and treatment for people with disabilities.
   4.1 The Coalition on Cardiovascular Disease and Diabetes in Indiana (CADI) will develop a special disability initiative.
   4.2 Local Healthy Community Coalitions will create memoranda of agreement with disability providers to better target people with disabilities and their families.
   4.3 Key stakeholder audiences will have heightened awareness of health disparities among people with disabilities and of actions being taken to improve the health of people with disabilities.
   4.4 ISDH will develop an effective training program to encourage and support the capability of health education/prevention programs to better reach people with disabilities.
   4.5 The "community health system" (low income clinics) will create a system-wide strategy to reach people with disabilities.
   4.6 Indiana will ensure that individuals who have special health care needs and disabilities across the life span will be fully included in all preventative, treatment, and intervention programs related to cardiovascular health.
5. Disability advocacy organizations are encouraged to select and emphasize activities which promote healthy habits related to cardiovascular disease.

5.1 Disability organizations will be well-connected to other disability or disease organizations to cross-support families and individuals.

5.2 Disability advocacy organizations will support the other health care needs of their constituents.

5.3 Individual disability advocacy organizations will incorporate physical activities, healthy food choices, and role modeling of “healthy choice” in their social and program activities.

6. Community organizations, programs, and services will ensure that people with disabilities will be included.

7. Cardiovascular health programs, services and equipment will be easily accessible and ADA compliant.

7.1 Cardiovascular programming will be offered in ADA compliant settings that are accessible by public transportation.

7.2 Every neighborhood will have a community health worker.

7.3 Every community health clinic will be equipped with specialized equipment, etc. to serve people with disabilities.

7.4 Community parks and recreation centers will be universally designed to increase access for individuals who have disabilities.

7.5 Adaptive physical activity programs will be developed and incorporated for individuals with physical disabilities in health and wellness programs.

7.6 Professionals and service providers will have a full understanding regarding disability access and rights to reasonable accommodations (ADA compliance).

7.7 Health Care organizations will document the existence and implementation of a plan to assure full access to services by individuals with disabilities across the life span, including physical access, translation services, and patient and family centered care.

7.8 Health care providers will be educated in best practices for serving persons with low hearing or deafness.

8. Direct support professionals and other community health workers receive training related to cardiovascular health and wellness for individuals with disabilities, and are supported to model wellness behaviors.

8.1 Developmental disability providers will proactively monitor the implications of prescribed medications on children's health.

8.2 Direct service providers will be trained to recognize "red flags" associated with acute cardiovascular events, diaphoresis, shortness of breath, inability to move around, etc.

8.3 Direct services providers will have rapid access to medical support when they are concerned regarding a patient's change in state of health, so that urgent action can be taken for "red flag" presentations of heart attack and stroke.

8.4 Standardized training modules for direct support staff related to promoting health and wellness will be developed.
8.5 The State will support requiring standardized curricula for DSP's in all areas of service, not just group homes.
8.6 Ivy Tech will uniformly provide continuing education for community health workers statewide.
8.7 Service provider agencies will strengthen non-smoking policies.

9. **Individuals and families will advocate to be included in community programs and services to support healthy outcomes around cardiovascular disease.**

10. **Individuals and families will have an understanding of lifestyle choices that impact their cardio-vascular health including those with special health care needs and disabilities across the lifespan.**

10.1 Individuals will have knowledge of healthy eating choices and the consequences of poor choices.

10.3 Children with disabilities will be able to make healthy food choices.

10.4 Children will have access to information about self-care in a way that is conducive to their learning style (assistive technology, visual support, etc.).

10.5 Adults with disabilities will be provided with and trained in self-management and assessment of their health (e.g. blood pressure, blood sugar, etc.) and illness self-care.

10.6 Families will have access to healthy cooking classes.

10.7 There will be a long range campaign that focuses on educating the younger population in the community and re-education the older population regarding healthy lifestyles.

10.8 A standardized “My Communication Needs” card will be used by people with specific communication requirements.

11. **Individuals, families, and other community populations will know and understand their rights to equal access to health care related to cardiovascular disease.**

11.1 Individuals and families will have a greater understanding of self-advocacy and how to practice it.

11.2 Individuals in communities will have a complete understanding of their rights to equal access.

11.3 Families will feel empowered to question/challenge their health care provider when discussing the implications of possible medications, dietary, and other changes.

11.4 Populations in the community will have full empathy and understanding of disability issues as it pertains to rights, services, characteristics, and the health promotion needs of their community.

11.5 Self-management plans for people with intellectual disabilities will be asset and ability-based.

12. **Health professionals have increased awareness of the higher risks and different presenting features of cardiovascular disease in individuals with intellectual and physical disabilities.**

12.1 "Routine" health care will be delivered at a more frequent periodicity for individuals at high risk; i.e. a once-a-year doctor visit is rarely adequate for a person with disability.
12.2 Nutrition will be assessed as part of the overall screening process.
12.3 Early indicators of risk will be identified, as opposed to first waiting for a diagnosis.

13. **Professionals are trained on how best to communicate with people with various disabilities.**
13.1 Professionals, including those in rural health centers and community health clinics, will be trained on how to communicate effectively with someone with a disability and have the "tools" to best explain not only the diagnosis but the treatment.
13.2 Professionals and service providers will use person first language when interacting with individuals with disabilities.
13.3 Any type of family support will be culturally competent, culturally knowledgeable and sensitive, and linguistically appropriate across communication modalities.
13.4 Training for effective communication will be provided to health care office personnel and volunteers.
13.5 Families with cultural differences will be able and willing to break down the cultural barriers when communicating with their healthcare professionals.
13.6 Organizations will follow up with patients with disabilities to insure communication is effective in the context of their medical and health care.
13.7 Special recognition will be provided to professionals and practices that engage in best practices around effective communication with patients who have disabilities.

14. **Private and public partnerships are developed to engage families with disabilities and other health care issues who live in low-income or rural areas to better provide support and services.**
14.1 Health providers will be aware of and have contact with community organizations to support their patients.
14.2 There will be increased use and support of community health workers.

15. **Youth with disabilities learn about healthy choices and habits that prevent cardiovascular disease in schools and other community settings.**
15.1 Youth receiving special services in schools will learn about avoiding bad habits; i.e., avoid smoking, with repetition throughout their school careers.
15.2 Children in schools will be supportive of their peers with health issues.
15.3 Empathy education will be a crucial component of school curricula.
15.4 Children will have access to information about the importance of self-care in a way that is conducive to their learning style (assistive technology, visual support, etc.).
15.5 Local school systems will develop disability-sensitive wellness policies and educational practices.
15.6 Classrooms will incorporate physical activity into their daily teaching (in the case where gym is not available).
15.7 A common curriculum will be developed to teach students and school staff about health issues in conjunction with disability awareness.
15.8 Schools will promote healthy habit training across the range of individuals receiving special services, with repetition throughout their school careers to reinforce the importance of health in the life course.
15.9 Youth and adults with disabilities will be incorporated into community programming for health education and physical activity - considering adaptive needs in the planning and delivery of programs.

15.10 Communities will include children who have disabilities in health, nutrition, and physical activity programs; those programs are adapted to meet individual needs.

16. Improved data and surveillance systems related to cardiovascular disease will be able to better quantify health outcomes of people with disabilities.

16.1 Data between BQIS and ISDH will be synthesized so that information can be better utilized to assess need.

16.2 The deaths of individuals who live in institutional settings including group homes (with the exception of hospice) will be subject to coroner review, improving clarity of the causes of death.

16.3 A uniform and effective method to break out disability data from local and statewide data gathering efforts will be developed, including utilization and needs assessment data within residential services.

16.4 The rate of cardiovascular disease for individuals who have disabilities will decrease annually to the same or to a lower rate than that of the general population.

16.5 Health systems develop and employ best practice protocols for serving individuals with disabilities as well as using population data to evaluate needs and services.

16.6 State data collection questions will be sensitive in language.

17. System coordination includes an assessment of and connection to adequate health care financing for Hoosiers with special health care needs and disabilities.

17.1 Wellness coordination services will be expanded to all HCB Waivers.

17.2 Indiana will accept Medicaid Expansion to support the preventive and cardiovascular health needs of Hoosiers who have disabilities.

17.3 Indiana will look to best practices in other states for programs to replicate.

17.4 ISDH and FSSA will coordinate preventive health efforts around cardiovascular disease for the Medicaid population including performance measures for Medicaid managed care.

17.5 Indiana will participate in the expansion of programs to insure people.

17.6 We will know how well the health and medical system serves people with disabilities.

18. Families will have adequate funding supports to ensure all members can access nutritious foods, medical care, and physical activity.

18.1 Adult and older adult caregivers of people with disabilities will be supported through DDRS and the Division on Aging.

19. Community cardiovascular health promotion activities are connected with "livable community" initiatives.

19.1 Local communities will address safe routes to school.

19.2 Neighborhoods will be safe and supportive of people with dementia.
19.3 Neighborhood livability initiatives will include people with disabilities.
19.4 Neighborhoods will be walkable and roll-able and will provide access to clean air, green space, physical activity, and fresh food.
19.5 Local communities will offer space for community gardens that are accessible to those with disabilities.
19.6 The "take one - give one" philosophy will be encouraged, instead of relying on "systems" – e.g., barter systems and community sharing will be encouraged.
19.7 Communities and neighborhoods will work with local farmers to offer fresh fruits and vegetables in locations that are in "food desert" areas.
19.8 There will be a shift to community-based services, emphasizing opportunity for healthy activities.

20. Peer-to-peer health support and education programs are established and expanded for people with disabilities.

21. Direct Support Staff are supported to model healthy behaviors in their work with individuals with disabilities.
21.1 Direct support staff will model healthy behavior when interacting with individuals with disabilities.
21.2 Direct care staff will have health care coverage for themselves and their families that addresses preventive care for cardiovascular disease.
21.3 Direct service workers will be professionalized and rewarded for increased educational accomplishments.
CANCER
Recommendations with Possible Action Steps

1. Physicians and other health care providers apply cancer risk factors, screening, prevention, and education protocols to people with disabilities.

2. Individuals and families are educated about the health issues related to cancer prevention and management (screenings, healthy habits, smoking, and other risk factors).
   2.1 Persons and caregivers will be educated in routine health education and prevention, including preventive screening recommendations and healthy habits.
   2.2 Families will be educated about the different kinds of cancer.
   2.3 Smoking by persons with persistent mental illness will be reduced.
   2.4 Children who have disabilities will be part of education efforts to address prevention.
   2.5 The importance of education about healthy sexuality for youth (and adults!) with disabilities and implement actions will be acknowledged.
   2.6 Self-Advocate groups will be educated about the importance of self-awareness of cancer prevention and treatment issues.

3. Disability Service Providers insure that clients under their care are receiving cancer prevention, screening, and education protocols by physicians and other health care providers.

4. Already existing health consortia / committees / task forces will ensure that people with disabilities will be included in their governance and policymaking
   4.1 Individuals and families will advocate to be included in community programs and services to support healthy outcomes around cancer.

5. Cancer screening and treatment facilities and equipment will be accessible.
   5.1 The availability of specialized gynecological and mammography services for people with disabilities throughout Indiana will be assessed and publicized.

6. Information regarding cancer screenings, prevention, risk factors, etc. is accessible and at an appropriate reading level using standards of universal design.
   6.1 Information regarding cancer screenings, preventions, risk factors, etc. will be accessible and at an appropriate reading level using universal design standards
   6.2 Educational levels of caregivers who are disseminating health-related information to people with disabilities will be assessed and support will be provided to improve their ability to assist with screenings, health exams, etc.
   6.3 Training videos on critical health care issues will be developed for people with intellectual disabilities.
   6.4 The participation of people with disabilities in palliative care programs and end of life counseling will be evaluated.
   6.5 Health education materials will be assessed for their accessibility of use by people with disabilities.
7. **Community organizations, programs, and service providers promote better outreach regarding cancer prevention and treatment for people with disabilities.**
   7.1 Information will be provided to various Health Consortia (e.g., committees, task forces, etc.) to promote better understanding of the issues of individuals with disabilities.
   7.2 Current practices will be assessed and, if needed, plans will be developed to more aggressively recruit women with disabilities to breast and cervical cancer screening programs.
   7.3 Regional Wise Women coordinators will be convened for networking/education about disability issues and assist with training for recruitment, adapting materials, etc.
   7.4 Advocacy/education organizations (coalitions) will have the supports needed to seriously address the disability issues within their mission and actively recruit people with disabilities into their structure.
   7.5 Disability-related goals will be incorporated into the forthcoming Cancer Control Plan.
   7.6 Persons with disabilities will be included in coalitions.

8. **Education is provided to health professionals about communicating with and adapting care for people with disabilities around cancer issues.**
   8.1 Physicians and other care providers will be trained to effectively communicate about cancer with people with disabilities.
   8.2 Access to screening will be ensured as recommended by CDC and related organizations.

9. **Disability service providers are educated about the health issues related to cancer prevention and management (screenings, healthy habits, smoking, and other risk factors) and support staff to model wellness behaviors.**
   9.1 Direct service providers will receive needed health education to sustain their own best health

10. **A variety of accessible technologies around cancer prevention and treatment are developed and/or promoted, and people with disabilities are supported to use them.**
    10.1 Phone applications as HELP will be evaluated and promoted.

11. **Improved data and surveillance systems related to cancer are able to better quantify health outcomes of people with disabilities.**
    11.1 Data collection about people with disabilities and incidence of cancer will be improved
    11.2 Wellness Coordination will continue to be offered as an available service, but data collection and outcome measurements will be included as a routine element of care.
    11.3 People who are diagnosed with chronic health conditions like cancer, diabetes, etc. will be included as a "person with a disability" under the ADA.
12. Disability advocacy organizations disseminate information and conduct outreach campaigns that increase awareness of cancer prevention and treatment.

13. Schools and community organizations adapt programs related to cancer prevention (health education, physical education, etc.).
   13.1 Schools will include adaptive health education in special education programs and include parents in curriculum development and practice.

14. State policies promote access to cancer prevention and treatment for people with disabilities.
   14.1 Policies that promote access to prevention and screening, (Medicaid Health Homes) will be ensured.
   14.2 Disability advocacy organizations will promote policies in health care systems and state systems to provide access to cancer prevention and treatment.
   14.3 Information on issues related to equal access to services will be routinely disseminated to consumers.
   14.4 Disability groups will communicate well regarding resources; silos will be eliminated.
   14.5 A sugar beverage tax will exist.

15. Communities and disability organizations promote access to wellness initiatives that prevent cancer.
   15.1 Information will be provided to Health Consortia, committees, task forces, etc., regarding characteristics of different disabilities to promote better understanding of the issues of individuals with disabilities.
   15.2 Plans will exist to more aggressively recruit women with disabilities to breast and cervical cancer screening programs (assess current utilization first).
   15.3 Regional Wise Women coordinators will be convened for networking/education around disability issues and will assist with training for recruitment, adapting materials, etc.
   15.4 Advocacy/education organizations (coalitions) will have the supports needed to seriously address the disability issues within their mission.
   15.5 Each coalition will aggressively recruit people with disabilities and their advocates into their structure.
   15.6 As the Cancer Control Plan expires in 2015, it will be timely to use this report as a vehicle to understand how best to incorporate disability-related goals into the plan.

16. Neighbors are empowered to provide support for people with disabilities who are experiencing cancer (or other chronic conditions).
OBESITY
Recommendations with Possible Action Steps

1. Care planning for overweight and obese individuals is improved, including school age children and those transitioning from adolescence to adulthood.
   1.1 Primary care will include weight management care for this population.
   1.2 The CYACC transition plan approach from pediatric care will be incorporated into adult care across Indiana.
   1.3 Continuity of care for people served intermittently through clinics and volunteer systems will be improved.
   1.4 Guides to best practices in serving people with disabilities will be disseminated to medical providers.
   1.5 Research-based definitions of overweight and obesity will be employed for sub-populations of people with disabilities.
   1.6 Primary care will include monitoring of nutrition (including lab tracking of malnutrition as needed).
   1.7 Physicians will help people with disabilities formulate a plan to decrease weight.

2. Physicians and other health care providers apply obesity risk factors, screening, prevention, and education protocols to people with disabilities of all ages
   2.1 Disability service providers insure that clients under their care are receiving obesity screening and education protocols by physicians and other health care providers.
   2.2 Community organizations, programs, and service providers promote better outreach regarding obesity and treatment for people with disabilities.

3. The importance of obesity as a diagnostic category is elevated, which provides patient access to medical reimbursement systems.
   3.1 Where appropriate, obesity will be cited as a health risk and resources will be directed to it in Medicaid Wellness Coordination plans.
   3.2 Access to and reimbursement for community weight loss programs will be expanded, including commercial programs such as Weight Watchers and others.
   3.3 Access to weight surgery for individuals who have existing disabilities will be considered in policy planning.
   3.4 Managed care programs, waivers and other programs will support reimbursement to community based wellness initiatives for their clients.

4. Private sector fitness program personnel are educated to include and accommodate people with disabilities.
   4.1 Access to rehabilitation exercise programs designed for people with mobility issues related to obesity will be ensured.
   4.2 Reach trade associations of fitness centers, etc., will receive training and support to reach out to and better serve people with disabilities.
5. **Educational workshops for individuals with disabilities and caregivers are provided about the risks associated with obesity and strategies for reducing obesity.**

5.1. The Health Matters peer-to-peer program will be implemented in Indiana communities.

5.2. The health seekers movement will be advanced through the support of evidence-based wellness classes for Health Seekers.

5.3. Age-ist associations with aging and weight gain will be reduced. The use of apps that help people with weight management will be identified and promoted.
RECOMMENDATIONS AND POSSIBLE ACTION STEPS

TO ADDRESS RISK FACTORS

The following are recommendations developed by the Task Force regarding the alleviation of risk factors that are associated with chronic diseases. There were four area of focus: improving nutrition, increasing physical activity, removal of environmental barriers including lack of accessibility, and tobacco reduction and cessation.

NUTRITION AND HEALTHY EATING
Recommendations and Possible Action Steps

1. Nutrition education programs/organizations reach out to people with disabilities (with accommodations).
   1.1 Purdue Extension will be engaged to support better nutrition for people with disabilities.
       1.1.1 Extension trainers will expand nutrition education for people with disabilities.
       1.1.2 There will be expanded participation of people with disabilities in Extension Homemaker Clubs statewide.
   1.2 Direct service professionals will be provided with information about local healthy eating programs and will assist them with expanding the inclusion of their clientele in these community-based programs.
   1.3 Existing commercial weight loss programs will better include and serve people with disabilities.
   1.4 Community supported agriculture (CSA) leaders will network and relate to the disability community at the local level.

2. Training in nutrition, cooking skills, shopping, food selection, etc. exists across the continuum of service providers (direct support professionals, in-home caretakers, family, etc.)
   2.1 A nutrition training program for DSPs will be developed and deployed statewide.
   2.2 Access to resources about healthy eating for direct service providers, other support personnel, and family caregivers will be provided.
   2.3 Basic cooking classes for DSP’s and others supporting people with disabilities, will be developed to provide healthy, safe and palatable meals.
   2.4 Health Home Services will monitor risk factors, including nutrition.

3. State policy and financial incentives promote healthy eating for people with disabilities.
   3.1 A statewide tax on sugar beverages will be created.
   3.2 Extra SNAP benefits for fresh foods will be provided for use anywhere (e.g., farmers’ markets, chain stores, gas stations, etc.).
   3.3 Medicaid will fund physician/NP ordered supplements and vitamins.
   3.4 State support and access to federal funding will be increased for local growers/providers to enhance local markets for fresh food.
4. Training and support for people with disabilities, living independently or with family, develops good nutrition habits and make healthy choices in cooking, food selection and preparation, etc.

4.1 Educational supports around good nutrition will be developed for workshop settings, local family support organizations, and in publications reaching individuals with disabilities and their family members.

4.2 Families will be taught to advocate for IEP and adult care planning that includes nutrition, healthy meal preparation, and supporting healthy choices in school lunches, dining out, and grocery shopping.

4.3 More individuals with disabilities and families will be engaged in growing fruits and vegetables.

5. Communities are supported to address the broad local issues around healthy eating for people with disabilities.

5.1 Local food coalitions and councils will address community issues around better nutrition for people with disabilities.

5.2 Availability of unhealthy food choices in public settings will decrease.

5.3 Provision of healthy eating options will be encouraged at events that include people with disabilities.

5.4 Local community chats will be hosted to promote better education about good nutrition.

5.5 Restaurants will increase their marketing efforts regarding healthy menu choices.

5.6 People with disabilities will be invited and involved in community gardening, food councils, and farmers’ markets.

5.7 There will be increased community gardening in neighborhoods where group homes are located.

6. Students with disabilities are included in ongoing school programs aimed at improving nutrition and healthy eating.

6.1 Access to resources about healthy eating will be provided for teachers

6.2 Availability of unhealthy food choices in school settings will decrease.

6.3 Schools will be required to develop K-12 nutrition/wellness and cooking programs for all children, including those with IEPs.

6.4 Students with disabilities will receive accommodations to enhance their participation in health education programs.

6.5 Basic nutrition will be a criterion for the completion of high school diploma programs.

7. Organizations that provide peer support for persons with disabilities (Self Advocates, CILs, Best Buddies, etc.) role model positive eating habits.

7.1 Self-advocates will receive funding to become leaders in wellness - eating well, losing weight, and quitting smoking.

7.2 Self-advocacy organizations will offer cooking classes on fresh food preparation.
8. People with disabilities are connected to media and resource formats that meet their needs to promote healthy choices.

8.1 Methods will be developed for state organizations to distribute Health and Wellness education and improve access to supports.

8.2 A disability-friendly healthy eating website will be developed and promoted.

8.3 Healthy meals cookbooks with/by/for Hoosiers with disabilities will be developed or promoted.

8.4 User-friendly food label interpretation/healthy eating phone applications will be developed or promoted.
INCREASING PHYSICAL ACTIVITY
Recommendations and Possible Action Steps to

1. informal community physical activity opportunities for people with disabilities that are accessible, inclusive, and adapted are expanded, developed, and/or maintained.
   1.1 Walking clubs will be formed in neighborhoods with group homes or other residents with disabilities.
   1.2 Creativity, competitiveness, and cooperation will be encouraged in the development of physical fitness challenges in families, schools, and communities.

2. Individuals with disabilities are empowered /to become more physically active.
   2.1 INshape Indiana and other similar public and commercial programs will incorporate information about accommodations for individuals with disabilities.
   2.2 Individuals will be encouraged to include an activity plan in their own person-centered plans, irrespective of institutionally-determined plans for groups.
   2.3 New methods will be used and supported to identify activity goals, desires, plans, and resources needed for individuals with disabilities.
   2.4 Existing physical activity programs will adapt to increase motivation to participate by people with disabilities.
   2.5 Social marketing techniques will be employed to increase physical activity by people with disabilities.

3. State funding policies are revised to support physical activity for people with disabilities
   3.1 Gym/health center memberships will be eligible for Medicaid funding or reimbursement.
   3.2 Bicycles will be an allowable Medicaid expense.
   3.3 The Michelle Obama’s Let’s Move! program in schools and adult service organizations will be expanded to include people with disabilities.

4. Accessible and adaptive physical activity programming for people with disabilities is expanded and staff receive training in disability awareness, rights, and modification.
   4.1 Local parks departments will promote therapeutic recreation programs.
   4.2 Physical activity programming in parks and recreation programs will be expanded for/with people with disabilities
      4.2.1 Parks and recreation departments will offer programs for those with disabilities (soccer, baseball, etc.)
   4.3 YMCA’s and other public and private healthy living organizations will be deliberately inclusive of people with disabilities.
   4.4 Access to organized sports for all youth will be increased, including those with special needs; e.g., by subsidizing cost for low income families.
   4.5 Personal fitness providers will receive training to enhance their ability to work with people with disabilities.
   4.6 Adaptive physical activity resources will be collected and effectively disseminated to service providers and the general public.
4.7 A statewide initiative/challenge will encourage service providers to improve their own health and knowledge about healthy living.

4.8 Individuals with disability and obesity will have access to rehabilitation exercise programs.

4.9 Fitness center trade associations will receive training and support to reach out to and better serve people with disabilities.

5. **Inclusive infrastructure planning encourages accessible physical activity for all.**

5.1 The reach of Indiana’s Complete Streets initiative will be broadened.

5.2 Group homes will be located on complete streets.

5.3 Sidewalk and lighting programs will be expanded at the local level, especially in areas unserved by parks.

5.4 Public spaces with sensory resources will be created to encourage interaction and exercise as a social activity.

5.5 Decisions around land use regarding the location of disability facilities and residences will prioritize proximity to healthy community resources such as fresh food groceries, parks, sidewalks, etc.

6. **School programming and extracurricular activities emphasize physical activities and assure modifications are available so that students with disabilities participate.**

6.1 Every Indiana school will provide support and outlets for daily moderate physical activity for every child.

6.2 Increased state funding will enable schools to fully fund a quality physical education curriculum that reaches every student.

6.3 All schools will be fully funded to include students who have disabilities on sport teams, using the 2013 Presidential Executive Order.

6.4 Secondary schools will increase emphasis on personal fitness and inclusive team sports and de-emphasize competitive team sports.

6.5 Pre-service training in adaptive physical education will be improved in Indiana Schools of Education.

7. **Inclusive and accessible community-based sports programs support year-round physical activity.**

7.1 Special Olympics and other similar programs will provide accessible, year-round sports opportunities to improve the health and well-being of individuals with disabilities at all ages.

8. **People are connected to new media and technology resources that promote physical activity.**

8.1 People with disabilities will have knowledge of and use pedometers.

8.2 People with disabilities will use smartphones, Fitbit, My Fitness Pal, and similar technologies and applications to promote physical activity.
ENVIRONMENTAL BARRIERS
Recommendations and Possible Action Steps

1. Transportation and other program access barriers that impede the inclusion of people with disabilities in health programs are addressed and resolved.
   1.1 There will be expanded affordable and inclusive transportation options at the local level.
   1.2 State contracting processes will include requirements to address inclusion through diverse representation on advisory groups and to track data specific to disabilities.
   1.3 Expansion of telemedicine will be explored as a tool to increase access to health related programs by people with disabilities.
   1.4 Support for research on health disparities of all kinds within Indiana will be expanded.

2. All community intervention materials related to health education and promotion are created in multiple alternative formats (large print, Braille, text to speech, languages).
   2.1 Appropriately-scaled literacy levels will be used in all educational and informational materials.
   2.2 Multiple alternative communication formats will be used in health education and promotion materials developed for public use.
   2.3 A higher standard of accessibility will be set for publicly available health-related websites.
   2.4 Health facility-based quality improvement programs for patient education will assess and expand their capability to serve people with disabilities, including new mothers with or caring for infants with disabilities and other patient groups.

3. All health care intervention and education programs follow principles of universal design, ADA compliance, and a commitment to serving all members of the community.
   3.1 All managed care contracts funded by the State must include guarantee of access.
   3.2 School will receive funding for the purchase of equipment for students with disabilities to participate in physical education classes.
   3.3 Accessible medical office equipment, practices, and critical areas for intervention will be identified and providers will be educated about them; e.g., exam tables that lower for people in wheelchairs, how to weigh someone in a wheelchair, screening techniques for those with complex bodies (mammogram, CT scan, etc.).
   3.3.1 Model medical offices will offer examples of accessible equipment, universal design, scales, ramps, etc.
   3.3.2 Assistive listening devices will be available in health care settings.
   3.3.3 Educational videos on ideal practice settings for serving people with disabilities will be created.
   3.3.4 There will be environmental improvements in design, acoustics, and accessibility with specialized training for office staff in communicating with people with disabilities.

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4. All community healthy lifestyle programs follow principles of universal design, ADA compliance and a commitment to serving all members of the community
   4.1 Community decision-makers will have and use expanded knowledge of the impact of environment on health.
   4.2 The ADA and universal design for local park systems will be enforced.
   4.3 All community health intervention programs (classes, exercise, training, support groups) will be 100% accessible in their locations.
   4.4 The ADA will be employed to better regulate the provision of accessible equipment in community fitness and exercise centers.
   4.5 Braille and other methods will be used to improve labeling in local groceries.

5. The ability of health and other professionals is enhanced to better provide support and care of people with disabilities.
   5.1 All health care providers and others in service and hospitality professions will receive training on accessible communication practices.
   5.2 Health professionals will improve their partnerships with their patients with disabilities, and will focus on functional outcomes as opposed to simple remediation of medical diagnoses.
      5.2.1 Health professionals will view their patients with disabilities as “people” with the same health and prevention needs as all their patients.
      5.2.2 Process improvement will be used in clinical settings to identify ways to effectively address individuals with special needs.
   5.3 The Indiana State Medical Association and other State health-related organizations will exhibit and support their leadership to improve the quality of care and quality of life for individuals with disabilities.
   5.4 Qualified persons with disabilities will be recruited into the health professions.

6. Greater health consumer self-advocacy is promoted and supported among people with and family members of people with disabilities.
   6.1 Individuals with disabilities will be educated about health, wellness, and prevention of secondary conditions.
   6.2 Research will be developed and conducted to increase the independence of persons with disabilities through peer-support models which improve access to community health care services.
   6.3 People with disabilities will have access to their personal health records.
TOBACCO USE AND SMOKING
Recommendations and Possible Action Steps

1. Primary medical care providers provide access to supports to stop smoking for people with disabilities and caregivers of children with disabilities.
   1.1 Primary medical care providers serving people with disabilities will provide access to patch, gum, and quitting supports.
   1.2 Preventive and support services for tobacco cessation will be fully covered in state provided managed care contracts without co-pay.
   1.3 Parents of children with disabilities will receive increased support for smoking cessation to reduce second hand smoke and diminish the culture of smoking.
   1.4 Parents of children with disabilities will receive education about the risks of smoking and second-hand smoke.

2. The State creates tangible incentives for smoking cessation.
   2.1 An increased state tax on tobacco products will fund expanded tobacco and e-cigarette prevention and cessation programs targeting people with disabilities and their families.

3. Communities advocate for municipal non-smoking ordinances.
   3.1 The number of municipal non-smoking ordinances in Indiana will be increased.
   3.2 Non-smoking ordinances will include e-cigarettes.

4. People with disabilities are free from exposure to smoking when accessing services and supports (community supports, transportation, including Medicaid cabs).
   4.1 Direct care staff will be supported in tobacco use cessation and the adoption of healthy behaviors, with financial incentives as often as possible.

5. Accessible smoking cessation programs are developed for individuals with disabilities and family caregivers.
   5.1 All educational materials for smoking cessation will employ alternative formats.
   5.2 People with disabilities will develop leadership skills to help peers and others end smoking
   5.3 Education on coping skills will be offered to individuals and sub-populations with disabilities who are attempting smoking cessation.
   5.4 Indiana’s Quit Now program will be adapted to better serve people with disabilities.

6. Data exist on health disparities related to tobacco use and its consequences for people with disabilities.
   6.1 Tobacco use data will be included in routine investigational health studies supported by the state.
7. **Workforce non-smoking policies are expanded.**
   7.1 State contracts will include requirements for enforcement mechanisms around smoke-free workplace rules
   7.2 Commercial enterprises will be supported to improve smoking policies and non-smoking practices.

8. **Community-wide smoking cessation efforts continue to be supported and expanded.**
   8.1 Develop comprehensive tobacco cessation plans and actions will be developed to creatively combine interventions and address both cultural and policy aspects of tobacco use.
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