



Inclusive Health Principles and Strategies: How to make your Practices Inclusive of People with Intellectual Disabilities

This resource provides principles and strategies to ensure the full and sustainable inclusion of people with intellectual disabilities in health policies and laws, programming, services, training programs, research, and funding streams.



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Executive Summary

People with intellectual disabilities (ID) are one of the most medically underserved groups in the world and are often left out of most aspects of the health system, which has resulted in significant health disparities for this population. The intent of **Inclusive Health**¹ is to support existing programs to become inclusive and accessible, rather than to create separate programs for people with ID. Including people with ID in existing health programs has the potential to improve health outcomes for people with ID while reducing health care costs for society. **This resource provides practical information for any organization in the broader health system on how to take the first steps to make their policies and practices inclusive of people with ID to help close this gap in health outcomes.**

People with ID face a number of barriers in the health care and public health system. Common barriers include:

- Attitudinal barriers – misconceptions that people with ID cannot live long and healthy lives
- Communication barriers – the use of complicated and inaccessible language
- Policy barriers – the lack of enforcement of existing laws regarding access to health
- Programmatic barriers – the failure to make reasonable accommodations for people with ID
- Social barriers – the conditions in which people are born, grow, live, learn, work, and age
- Physical barriers – structural challenges that block mobility

The four strategies outlined in this resource were created to help address these barriers and formed under **two foundational principles of Inclusive Health: Equitable Access and Full Participation**. Equitable Access means ensuring that people have access to the services and resources necessary to achieve their full health potential. Full Participation means that people with ID are fully and meaningfully included in health programs and services.

Organizations across the public health system can take action to remove barriers and improve access for people with ID to their services, as their patients, customers, beneficiaries, and clients. Here are the **four strategies** to help you start:

1. **Welcoming Spaces:** Ensuring your programs and physical spaces are accessible and welcoming to people with ID.
 - Incorporate disability etiquette, including for intellectual disability, into internal staff training.
 - Speak directly to the individual, not his or her companion, and let the person finish before responding.
 - If you offer assistance, wait for the offer to be accepted and for specific instructions. If you aren't sure what to do, ask.
 - If you are having difficulty understanding a person, it is ok to ask them to repeat themselves.
 - Operate under the assumption that people with ID are capable of making their own decisions.

¹ Inclusive Health is the inclusion of people with ID in mainstream health policies and laws, programming, services, training programs, research, and funding streams.

- ❑ Explore how using Universal Design – the design of services or physical environments to be useable by all without adaptation – may be applied to your services or organization.
 - ❑ Ensure your space or programs are in compliance with the Americans with Disabilities Act. Where possible, ask people with ID if there is a particular accommodation that might help them better use or benefit from your services.
- 2. **Communication:** Ensuring your communications, including written and spoken language, materials, and interactions with the community are accessible to people with ID.
 - ❑ Use accessible language.
 - Written materials should be in plain language, at no more than a sixth-grade reading level.
 - Language should get to the point and avoid jargon, acronyms, and abstract statements.
 - ❑ Provide in-person assistance to ensure individuals understand materials and are able to complete forms.
 - ❑ Include images of people with ID in your promotional materials.
 - ❑ Materials should also be available in other accessible formats like braille and large type.
- 3. **Awareness and Training:** Understanding your community and training your staff on the barriers and challenges faced by people with ID, including on how to remove them.
 - ❑ Train staff and leaders on the barriers faced by people with ID and methods for how to overcome those barriers.
 - ❑ Hire people with ID to provide input on and/or conduct the training.
- 4. **Sustainable and Intentional Inclusion:** Building intentional and sustainable inclusion by changing organizational culture to value and understand inclusion.
 - ❑ Embed inclusion into your organizational culture.
 - Incorporate disability rights and access into company policies and mission statements, including diversity statements.
 - Incorporate inclusion into each program, service, or activity you offer.
 - ❑ Partner with local disability organizations to learn how you can improve your inclusive practices.
 - ❑ Include people with ID in the planning, implementation, and evaluation of programs, services, or activities.
 - ❑ Hire people with ID to work at your organization in a meaningful capacity, both as a way of promoting a culture of diversity and inclusion and as an effective way to increase awareness of the need for inclusive practices.

The above strategies will help organizations embark on the first steps to adopting Inclusive Health. However, the beginnings of your Inclusive Health journey can come from simply engaging and interacting with people with ID. While there are many programmatic and operational changes recommended in this document, the first steps can stem from simply asking people with ID in your community how your program or service could work better for them.

Background

As the world's largest sports and public health organization for people with intellectual disabilities (ID), Special Olympics has been changing lives since 1968. Since the creation of the Special Olympics Health Program over twenty years ago, it has made life-changing and life-saving strides in health, providing health screenings and training health care professionals to improve access to quality health services and programs for people with ID. Despite the success of the health program, people with ID remain one of the most medically underserved groups in the world, and are frequently locked out of most aspects of health systems. As the result, people with ID face significant health disparities.

To improve the health outcomes for all people with ID and not just their athletes, in 2016 Special Olympics introduced a strategy: **Inclusive Health**. Building on the foundation of its health programming, Special Olympics aims to ensure that **the inclusion of people with ID in mainstream health systems becomes common practice**. *Inclusive Health Principles and Strategies: How to make your Practices Inclusive of People with Intellectual Disabilities* provides national-, state-, and local-level organizations with practical ideas and strategies to help move toward the full and sustainable inclusion of people with ID in all parts of the health system. To this end, Special Olympics engaged a workgroup of experts on disability and health – including people with ID and their family members – to develop these foundational principles and strategies.

Intellectual Disabilities

According to the American Association on Intellectual and Developmental Disabilities (AAIDD), intellectual disability (ID) is characterized by significant limitations in intellectual functioning and adaptive behavior which originates before age of 18. Intellectual functioning impacts areas such as learning, reasoning, and problem-solving.² Adaptive behavior is the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives.

Adaptive behavior includes:

- Conceptual skills—language and literacy; money, time, and number concepts; and self-direction.
- Social skills—interpersonal skills, social responsibility, self-esteem, social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
- Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, and use of the telephone.

Historically, society has had low expectations of people with ID, viewing them as incapable of engaging in community life. In reality, people with ID can and do live full lives in their communities. Most people with ID live independently or with their families without any formal supports. People with ID have jobs and seek access to the same services and amenities as people without disabilities. However, people with ID continue to face barriers to health.

Audience

The public health system includes anything and anyone that has an impact on people's health. This ranges from traditional medical care to the availability of healthy food and exercise. This

² <https://aidd.org/intellectual-disability/definition#.WyE21FUzonQ>

resource is intended to provide practical information for any organization in the health system on how to take the first steps to make their policies and practices inclusive of people with ID. The intent of Inclusive Health and of these strategies is to support existing programs to become inclusive and accessible, rather than to create separate, parallel programs for people with ID.

Some of the organizations that can benefit from this resource are:

- Health promotion providers, such as fitness centers, parks departments, or public health programs
- Health care providers, including physicians and other health care providers, hospitals, and clinics
- Social service providers that engage in health-related activities, such as community centers or sports clubs
- Social service agencies providing food, housing, transportation, or other social influencers of health
- State and local-level nonprofit organizations engaged in public health
- Professional associations of health care providers and others in the public health system
- Businesses and corporate entities engaged in public health or health-related services
- Grant makers and other funders
- Researchers in the field of public health, health care access, and health policy

Why Inclusive Health?

People with intellectual disabilities are one of the most underserved groups in the world.

Because of a range of systemic challenges, including inadequate provider training and inaccessible facilities, they have less access to quality health care and health promotion programs. As a result, people with intellectual disabilities (ID) experience dramatically higher rates of preventable health issues. According to the National Council on Disability, people with ID face a “constellation of health and health care disparities, including inadequate health and wellness promotion and inconsistent access to high-quality health care services.”³ The Centers for Disease Control and Prevention (CDC) defines health disparities as “preventable differences in disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations.”⁴ People with ID face significant health disparities, including higher rates of obesity;⁵ higher rates of diabetes, chronic pain, and cardiovascular disease.⁶ These health disparities are usually not the result of the individual’s disability but of the inadequate access to health care and other health services that people with ID experience.

Many of these disparities are rooted in barriers faced by people with ID in communities and health promotion systems. Since men, women, and children of all backgrounds (including age, race, gender, and socioeconomic status) live with ID, it is important to understand the intersection of ID with a person’s background and culture. People with ID from other groups that experience disparities – such as racial and ethnic minorities or other underserved communities – may face even greater barriers to health. Sometimes, people with ID also have

³ https://www.ncd.gov/rawmedia_repository/Od7c848f_3d97_43b3_bea5_36e1d97f973d.pdf, page 86.

⁴ <https://www.cdc.gov/aging/disparities/index.htm>

⁵ https://www.ncd.gov/rawmedia_repository/Od7c848f_3d97_43b3_bea5_36e1d97f973d.pdf, page 180

⁶ http://autisticadvocacy.org/wp-content/uploads/2014/04/MUP_ASAN_PolicyBrief_20140329.pdf, page 13.

other co-occurring disabilities, including physical disabilities, blindness, or may be deaf or hard of hearing.

The types of barriers faced by people with ID are:

- **Attitudinal barriers** include stigma, stereotypes, and misconceptions related to having a disability. These misconceptions include ideas that people with ID do not understand or are not deserving of respect, or cannot live long and healthy lives. For example, public health departments may not include people with ID in their health promotion efforts based on their implicit bias that people with ID cannot improve their health.
- **Communication barriers** include ways in which communications are not accessible. Inaccessible communication results from the use of complicated or technical language, long sentences, text-heavy dense forms, and words with many syllables. Barriers can also include lack of alternative formats such as braille and large type for users with multiple disabilities.
- **Policy barriers** arise from lack of laws and regulations requiring access, or lack of enforcement of existing laws. Policy barriers may also arise from official documents and operating guidelines of organizations. Examples include health insurance reimbursement policies that assume all people can be served in a 15-minute visit.
- **Programmatic barriers** arise when organizations fail to make reasonable accommodations to their programs or operations. Examples include inflexible appointment scheduling, insufficient time for appointments, meetings, or classes.
- **Social barriers** relate to the conditions in which people are born, grow, live, learn, work, and age – also known as social determinants of health. People with ID are more likely to experience these barriers than people without ID. These barriers include lack of financial resources, unemployment, lack of stable housing, and the experience of personal violence.⁷
- **Physical barriers** include structural barriers that block mobility. These include steps or curbs, medical equipment that requires a person to stand or step, heavy doors, or other spaces that require a person to reach high or crouch low. People with ID sometimes have physical disabilities as well, and are impacted by these barriers.

Inclusive Health is founded on the idea that these disparities can be addressed by removing these barriers and appropriately including people with ID in the mainstream health care system, health promotion, and public health efforts. Sustainable inclusive policies and practices can address, reduce and often eliminate many of these barriers. Inclusion allows for people with ID to take full advantage of the benefits of the same health programs and services experienced by people who do not have ID, resulting in improved health outcomes for people with ID.

⁷ Adapted from the CDC: <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html>

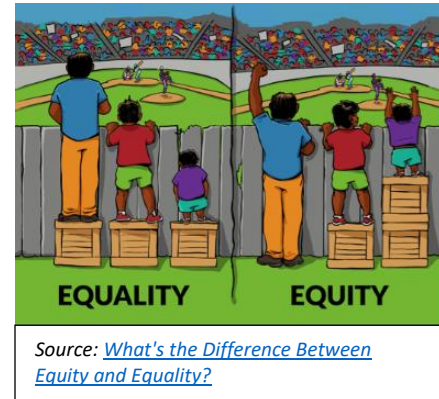
Principles of Inclusive Health

The foundational principles of Inclusive Health are: Equitable Access and Full Participation.

Principle 1: Equitable access for people with intellectual disabilities to all health programs, services and activities

Understanding the difference between equality and equity is important and is a key component to both reducing disparities and successfully including people with ID.

- **Equality** ensures that everyone gets the same things and aims to promote fairness. This can only be achieved if everyone starts from the same place and has the same needs, which is not the case for people from underserved populations such as people with ID.⁸
- **Equity** involves understanding and giving people what they need to live healthy lives. According to the CDC, health equity is when every person has the opportunity to "attain his or her full health potential" and no one is "disadvantaged from achieving this potential because of social position or other socially determined circumstances."⁹



What does this mean? It means everyone should not have the same resources, but instead have the necessary resources to achieve optimal health outcomes. Supporting health equity requires addressing barriers that prevent inclusion of people with ID in health programs, policies, and services.

Principle 2: Full participation of people with intellectual disabilities in all health programs, services and activities

Organizational policies and practices should integrate accessibility and accommodations for people with ID to allow for full and meaningful participation. To be inclusive of people with ID, their input should be requested and embedded throughout all aspects of program planning, development, and implementation. This is important in inclusion because people with ID can speak to their needs and provide applicable input leading to progress or success in a program or the objectives of an organization. People with ID can also aid in the evaluation of the program at different phases to support continuous improvement.

⁸ <http://sgba-resource.ca/en/concepts/equity/distinguish-between-equity-and-equality/>

⁹ <https://www.cdc.gov/nccdphp/dch/programs/healthycommunitiesprogram/overview/healthequity.htm>

Strategies for Achieving Inclusive Health

Achieving Inclusive Health is a journey, and this document provides four strategies for Inclusive Health. The first two strategies – creating Welcoming Spaces and ensuring Accessible Communications – are the first steps to including people with ID in programs and services. The second two strategies – Awareness and Training and Intentional and Sustainable Inclusion – provide strategies to cement your efforts and ensure that inclusion is sustainable. Details on the strategies, including further detail, quick tips, and resources are listed below.

1. Welcoming Spaces: Ensuring your programs and physical spaces are accessible and welcoming to people with ID will help you get started on including people with ID

| What to Do | Quick Tips | Help to Do It |
|----------------------------|--|---|
| Learn disability etiquette | <p>Sometimes, people feel awkward or avoid interacting with people with intellectual disabilities. To ease interactions, learn these elements of disability etiquette and incorporate it into staff training.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Speak directly to the individual, not his or her interpreter or companion, and let the person finish before responding. <input type="checkbox"/> If you offer assistance, wait for the offer to be accepted and for specific instructions. If you aren't sure what to do, ask. <input type="checkbox"/> If you are having difficulty understanding a person, it is ok to ask them to repeat themselves. <input type="checkbox"/> Do not touch a person with a disability or their mobility aid unless invited. <input type="checkbox"/> Act under the assumption that people with ID are capable of moving through the world and making their own decisions. <input type="checkbox"/> Don't talk "down" or use "baby talk" to a person with ID, instead communicate as you would with any other person of that age. <input type="checkbox"/> When speaking to someone with a vision impairment, always identify yourself and who may be with you. | <p>Disability Etiquette</p> <p>Talk to Me: Treating People with Intellectual Disabilities with Respect</p> <p>Mary's Top 10: Communication Tips</p> <p>Tips for Interacting with People with Disabilities</p> |
| Explore universal design | <p>Universal design rests on the idea that improving accessibility for people with disabilities will improve usefulness for all. Rather than providing separate adaptations for people with disabilities, systems and programs should be designed to be useable by all. For example, you may find that everyone benefits from the use of plain language in materials and documents.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Provide easily understandable documents that use simple wording and avoid jargon. <input type="checkbox"/> Ensure sufficient staff are available to assist customers with questions. | <p>Universal Design: Process, Principles, and Applications</p> <p>Universal Design Learning Guidelines</p> <p>Fact Sheet: Universal Design</p> |

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| | <ul style="list-style-type: none"> <input type="checkbox"/> Use multiple methods of communication, such as using both pictures and words. <input type="checkbox"/> Ask for feedback from people with ID. | |
| Comply with the ADA and provide reasonable accommodations | <p>The Americans with Disabilities Act (ADA) is a comprehensive civil rights law that prohibits discrimination in public accommodations and other public services. While the ADA is often associated with physical access only, it also requires provision of other reasonable accommodations to people with other disabilities. An accommodation is any change to an environment or the way things are done to help a person with a disability participate.</p> <ul style="list-style-type: none"> <input type="checkbox"/> If your organization has repeat customers or interactions, ask individuals with ID what accommodations they may need. <input type="checkbox"/> Plan ahead for potential accommodations needed, such as flexible or longer appointment times. <input type="checkbox"/> Train staff on how to ask if people need accommodations (see more under Disability Etiquette). <input type="checkbox"/> Ensure your programs and physical spaces are compliant with the ADA, using free resources available from the ADA National Network and others. | <p>ADA National Network: Find Your Regional Center</p> <p>Resources for Facilitating Inclusion and Overcoming Barriers</p> <p>Inclusion Strategies</p> <p>US Dept. of Labor - Accommodations</p> <p>Accessible Meetings & Events Guide</p> |

2. Communication: Ensuring your communications, including written and spoken language, are accessible to people with ID so they can fully participate and benefit

| What to Do | Quick Tips | Help to Do It |
|-------------------------|---|--|
| Use accessible language | <p>Providing easily understandable information is an accommodation for people with ID that can improve your program for everyone. In general, organizations should use “person first” language in communications with people with ID, unless an individual requests otherwise.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Write program materials in plain language and at no more than a sixth-grade reading level. <input type="checkbox"/> Avoid a high density of text and incorporate pictures to show meaning. <input type="checkbox"/> Avoid jargon and complex or abstract statements. For example, say “put your coat on” instead of “get ready.” Use frequent, concrete examples. <input type="checkbox"/> Provide in-person assistance to help explain or read materials or to complete forms. <input type="checkbox"/> Include photos of people with ID in your materials. <input type="checkbox"/> Offer materials in multiple formats, including audio/video, braille, large type, and printed copies of electronic documents. | <p>America's Health Literacy: Why We Need Accessible Health Information</p> <p>Plain Language Strategies (webinar archive)</p> <p>Communication Skills</p> <p>Accessible Print Materials</p> <p>Portrayal of People with Disabilities</p> <p>People First Language</p> |

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| | <ul style="list-style-type: none"> ❑ Offer plain language materials in the languages prevalent in your area, in order to serve people with ID whose primary language is not English. | Inclusive Image Libraries |
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3. Awareness and Training: Understanding your community and training your staff on the barriers and challenges faced by people with ID and how to remove them, in order to cement the accessibility efforts to create welcoming spaces and provide accessible communication

| What to Do | Quick Tips | Help to Do It |
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| Train staff on the barriers experienced by people with ID in accessing health services | <p>Training staff on barriers and how to overcome them is key to ensuring inclusion and sustainability of inclusive practices.</p> <ul style="list-style-type: none"> ❑ Incorporate intellectual disabilities awareness into staff training and professional development. ❑ Hire people with ID to conduct, advise, or participate in trainings and compensate them for their efforts. ❑ Training should include information on unconscious biases, including misconceptions that people with ID are incapable of learning, can't work or do not have a social/personal life, are unable to make decisions, or don't know what they want. ❑ Training should include common access needs of people with ID and information provided above on creating welcoming spaces and accessible communication. ❑ Training can include asking staff to identify existing policies and procedures that might unintentionally inhibit access for people with ID. ❑ Partner with local disability organizations to help with training | <p>Common Barriers to Participation Experienced by People with Disabilities</p> <p>Confronting and Addressing Conscious and Unconscious Biases and the ISMs</p> |

4. Intentional and Sustainable Inclusion: Build intentional and sustainable inclusion by changing organizational culture to value and understand inclusion

| What to Do | Quick Tips | Help to Do It |
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| Embed Inclusion in organizational culture | <p>Inclusive efforts are more likely to be sustainable if they are part of organizational culture and policies.</p> <ul style="list-style-type: none"> ❑ Incorporate disability, including ID, into organizational policies, statements, or mission, especially diversity statements. ❑ Model inclusion by leadership by having people with ID in influential roles or as meaningful advisers to leaders. ❑ Incorporate inclusion, including pragmatic tips, into professional development opportunities. | <p>AUCD Diversity and Inclusion Toolkit</p> <p>Painting a deeper picture of disability inclusiveness: Changing organizational culture and climate</p> |

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| | <ul style="list-style-type: none"> ❑ Assess staff knowledge and attitudes toward people with ID and identify areas that need particular attention. Repeat the assessments to track improvements in attitudes. | Why is it Important to Sustain Inclusion Efforts? |
| <p>Ask people with ID about the barriers they face and what is important to them</p> | <p>People with ID do not have all the same needs or face the same barriers. Barriers are sometimes heightened due to intersecting social and cultural factors such as race, gender identity, or socioeconomic status. It may be difficult or impossible for a person to distinguish barriers related solely to their disability from other intersecting factors in their life.</p> <ul style="list-style-type: none"> ❑ Engage in a respectful dialogue to identify the needs and barriers of people with ID. ❑ Ask people with ID to serve on advisory boards or leadership committees. ❑ Engage with people with ID individually or in small groups (in addition to advisory boards, if applicable). ❑ Once you have repeat customers or relationships with community members with ID, ask what particular barriers they face to learn more about them and the community. | Common Barriers to Participation Experienced by People with Disabilities |
| <p>Partner with local disability organizations</p> | <p>Local organizations may be able to direct or provide connections to similar organizations that are inclusive or making strides to provide ideas or lessons learned from their efforts.</p> <ul style="list-style-type: none"> ❑ Partner with local organizations in the community that have expertise in ID and serve people with ID and their families (for example, chapters of The Arc or Special Olympics, DD Councils, University Centers for Excellence in DD, or self-advocacy organizations, such as People First.) ❑ Invite their representatives to present at staff training or join advisory committees. ❑ Ask disability organizations how your organization can better include people with ID. | Directory of Community-Based Organizations Serving People with Disabilities |
| <p>Include people with ID in every phase of your efforts, including evaluation</p> | <p>Including meaningful input from people with ID will improve the effectiveness of your inclusive efforts. True inclusion requires speaking with and listening to the feedback of community members, including people with ID and their family members.</p> <ul style="list-style-type: none"> ❑ Include people with ID in planning new initiatives. Prior to creating a new initiative/program, include people with ID in the planning phases. Their feedback and input should be embedded throughout each phase of the program. ❑ Ask people with ID for their input – how do they envision this effort being implemented and where do they see themselves within the program? Make sure | Monday Mile case study Implement and Evaluate Strategies to Include People with Disabilities in Public Health Programs |

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| | <p>you understand how they experience your programming, services, and/or policies.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Include people with ID in evaluation of your efforts. <input type="checkbox"/> Continue to improve inclusive efforts by following up with people with ID and their family members or support person to see if your changes have made a difference. | |
| Hire people with ID | <p>Hiring people with ID, while not enough on its own, can help promote a culture of diversity and inclusion and can be an important step toward achieving inclusive practices. Hiring people with ID, especially in roles throughout your organization, will help entrench the importance of inclusion with all staff.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Hire people with ID for relevant positions. <input type="checkbox"/> Reach out to self-advocate organizations and/or organizations that work with people with ID to find applicants or post jobs. | <p>Using Plain Language to Enhance eRecruiting</p> <p>Employer Assistance and Resource Network on Disability Inclusion (EARN)</p> <p>Inclusion@Work: A Framework for Building a Disability-Inclusive Organization</p> |

Conclusion

People with ID are part of one of the most medically underserved groups in the world. Millions with ID lack access to quality health care and experience dramatically higher rates of preventable disease, chronic pain and suffering, and premature death in every country around the world. Inclusive Health addresses the health disparities faced by people with ID by ensuring their meaningful inclusion and participation in health care and health promotion policies and practices. These principles and strategies are intended to help anyone working in the public health system – anything and anyone that has an impact on people’s health – to take the first steps to effectively include people with ID.

The principles and strategies included in this document support the assertion that disparities can be addressed by including people with ID in the mainstream health care system and public health efforts, not by creating separate programs for people with ID. However, Inclusive Health can start small. We encourage you to start with the recommendations in the Welcoming Spaces section. Instituting these quick tips will help you start engaging in authentic and one-on-one interactions that will help you get to know the people with ID in your community and address their needs and concerns. Inclusive Health can grow from simple human interactions with people with ID in your community. Ask them about the barriers they face, or if there is a way your program could serve them better. People with ID are, most importantly, people living in and participating in the world and your community.

Special Olympics asks you to join us in achieving Inclusive Health. Everyone has the same right to health. Don’t wait for someone else to make it happen.

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Contributing Authors

Tanisha Clarke, MPH, *Senior Program Manager, Disability and Public Health, Association of University Centers on Disabilities (AUCD)*

Adriane K. Griffen, DrPH, MPH, MCHES®, *Senior Director of Public Health and Leadership, Association of University Centers on Disabilities (AUCD)*

Daphnee Guillaume, MPH, CHES, *Public Health Program Manager, Association of University Centers on Disabilities (AUCD)*

Charles Drum, MPA, JD, PhD, *Visiting Scholar, American Association on Health and Disability (AAHD)*

Rachel Patterson, MPA, *Senior Consultant, Health Management Associates*

Workgroup Members

Jack M. Brandt, MS, *Disability Policy Specialist, Partnership for People with Disabilities, Virginia Commonwealth University, Richmond, VA*

Leslie Cohen, JD, *Director, Sonoran Center for Excellence in Disabilities, University of Arizona, Phoenix, AZ*

Nell Coonen-Korte, *Special Olympics MN Athlete/Ambassador and SONA Health Messenger, Special Olympics Minnesota, Shakopee, MN*

Sara Lyons, MPH, CHES, *Program Analyst, Health and Disability, National Association of County and City Health Officials (NACCHO), Washington, DC*

Lindsey Catherine Mullis, MS, *Health & Wellness Director, Human Development Institute, University of Kentucky, Lexington, KY*

Ilka Riddle, Ph.D., *Director, University of Cincinnati Center for Excellence in Developmental Disabilities, University of Cincinnati, Cincinnati, OH*

Derrick Willis, MPA, *Associate Director, Center for Disabilities and Development, Iowa University, Iowa City, IA*

Expert Reviewers

Sheila Burgess, *Hockomock Area YMCA*

Roberta Carlin, MS, JD, *American Association on Health and Disability (AAHD)*

David Ellsworth, MPH, CHES, *Ohio Disability and Health Program, Nisonger Center - UCEDD*

Michael H. Fox, ScD, *Georgia Institute of Technology*

George S. Gotto, Ph.D., *University of Missouri Kansas City, Institute for Human Development (UCEDD)*

Lauren Griffiths, MPH, CHES, *Human Development Center, Louisiana State University*

Nip Ho, *Special Olympics Hawai'i*

Matt Holder, MD, MBA, *Lee Specialty Clinic*

Alice Lenihan, *Special Olympics International*
Michelle Manfredi, *Special Olympics Hawai'i*
Renee Manfredi, *Special Olympics Hawai'i*
Roy McConkey, OBE, PhD, *Ulster University*
Maegen Miller, *Special Olympics Rhode Island*
Lindsay Naeder, *Autism Speaks*
William H. Neumeier, Ph.D., *UAB/Lakeshore Foundation Research Collaborative*
Theresa Paeglow, *Independent Consultant, Disability Policy, Advocacy and Inclusion*
Mary Pittway, MA, RDN, *Special Olympics International*
Nicole Pratt, *SPAN Parent Advocacy Network*
Cordelia Robinson Rosenburg, Ph.D., RN, *University of Colorado School of Medicine, Pediatrics and Psychiatry*
Mary Ellen Seaver-Reid, M.Ed. ATP, *University of Vermont, Vermont LEND Program, Vermont I-Team – Center on Disability and Community Inclusion*
Lyubov Slashcheva, DDS, FABSCD, *American Academy of Developmental Medicine and Dentistry*
Deepa Srinivasavaradan, *CDC's Act Early Ambassador to NJ, Family Liaison to the Friends of NCBDDD*
Laurence Taggart, PhD, *Ulster University*
Kerri Vanderbom, Ph.D., *UAB/Lakeshore Foundation Research Collaborative*
Jane D. Wargo, *Presidential Youth Fitness Program*
Kiyoshi Yamaki, Ph.D., *University of Illinois at Chicago, Disability and Human Development*

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