

INDIANA COMPREHENSIVE STATE PLAN FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDER



INDIANA INTERAGENCY AUTISM COORDINATING COUNCIL

December 2022 Revision



GOALS OVERVIEW

The primary mission of the **Indiana Interagency Autism Coordinating Council (IIACC)** is to facilitate the efficient and effective exchange of information on autism-related activities among member agencies, to leverage resources and experiences to address common issues and outcomes, and to work towards fulfillment of identified areas of need. The Council serves as a forum to assist in implementation by informing the direction and assisting in increases of public understanding and awareness of the state's collective priorities, activities, programs, policies, and research. In addition, the Council serves to bring important matters of interest forward to enable and facilitate shared knowledge, discussion, and general access to state and organization resources and activities. In the current work, the IIACC serves as one.



Goal 1: Facilitation of IIACC Vision and Implementation



Goal 2: Family, Professional & Interprofessional Partnerships



Goal 3: Early and Continuous Developmental and Medical Screening for ASD



Goal 4: Access to ASD Health, Mental, Education, and Social Services For Individuals with ASD



Goal 5: Successful Youth Transition to Adult Services, Work, and Independence



Goal 6: Adequate Equitable Access to Resources, Funding, Inclusive Community, and Basic Living Conditions to Meet Quality of Life Outcomes



Goal 7: Justice System & Public Safety



Goal 8: Culturally Responsive Implementation

GOAL 1 Facilitation of IIACC Vision and Implementation

Goal Statement

- Share general and specific resources on autism spectrum disorder with providers, families, community advocates, and others who interacts with people with autism spectrum disorder in the community
- Improve access to resources on autism based on common and identified needs within the state
- Increase information sharing among decision makers about needs related to autism spectrum disorder across communities.

Action Plan

The following steps will help movement to support the current goal:

- Share information about the IIACC and activities that help meet goals of the Comprehensive Plan
- Invite people with autism spectrum disorder (ASD), providers, family and community advocates and other community members who support people with ASD to join IIACC activities

Sample Products



Zoom Backgrounds to Promote Unity



About IIACC - Informational Video



Autism Acceptance Month Slides with IIACC Information



IIACC Member Testimonials

GOAL 2

Family, Professional, and Interprofessional Partnerships



Goal Statement

- Identify needs and access barriers to learning, information, and integration of care across people with ASD, families, providers, and community.
- Share learning events to help people with autism spectrum disorder, families, educators, providers, and community members build awareness, partnerships, and relationships.

Action Plan

The following steps will help movement to support the current goal:

- Build knowledge of autism spectrum disorder and other disorders that are common for people with ASD
- Share tools that help build partnerships and knowledge among self-advocates, families, specialists, and communities using INformation Network website, IIACC social media, and newsletter
- Develop and support the Autism INformation Network where we can share resources and strategies from local, state, national, and global authorities on autism
- Share Indiana resources that help build awareness and knowledge across specialists and families.
- Build a shared place for people with ASD, families, specialists and communities to share information and build awareness.
- Connect with agencies and groups across Indiana to gain input and promote awareness of common tools and strategies
- Inform the Indiana community about IIACC news and statewide events through the IIACC social media means (e.g., newsletter, Facebook)
- Communicate current needs and barriers to state and local government personnel and other leaders. These needs and barriers are identified with the help of the Indiana Needs Assessment (conducted by HANDS in Autism®), and state and national data

Sample Products



Infocards and support resources for social media to disseminate goal-relevant information

AIDET & PATIENTS WITH AUTISM

- A ACKNOWLEDGE**
 - Address the patient directly, even if they do not look at you.
 - Draw their attention by calling their name and standing within the proximity
- I INTRODUCE**
 - Introduce yourself
 - Speak clearly. Give time to process information
 - Don't get frustrated if the patient does not answer the question the way you expected
- D DURATION**
 - State expectations honestly (e.g., "I'll squeeze your arm lightly")
 - Use visual supports (e.g., countdown board) to indicate time and pictures to explain the process)
- E EXPLAIN**
 - Tell what to DO instead of what NOT to do, e.g., "arms to self instead of don't fidget"
 - Explain what you are going to do before doing it.
 - Model behaviors or steps as needed
 - Repeat instruction if no response happens, but give time to process it first
- T THANK**
 - Take an interest in what the patient wants to talk about to ease and engage
 - Praise for the steps completed correctly or good behavior (e.g., great job sitting still)

INDIANA INTERAGENCY AUTISM COORDINATING COUNCIL (IIACC)
IndianaNetwork.org

SUPPORTING PATIENTS WITH AUTISM IN MEDICAL OFFICES

- COMMUNICATION & INTERACTION**
 - Connect with patient first by taking an interest in them
 - Avoid talking just to distract, as it is overwhelming for a patient with ASD
 - Be patient! Use simple and concrete sentences, avoid idioms or unnecessary words.
 - Represent instructions visually (visual schedule, cue cards)
 - Praise for appropriate actions
 - Avoid reprimands for undesirable behaviors
 - Avoid talking about individuals in their presence
- SENSORY ISSUES**
 - Use natural light; dim or turn off fluorescent lights; give patient headphones and sunglasses to block noise/light
 - See your patient with ASD in a quiet room (e.g., corner office)
 - Avoid unnecessarily physical contact (e.g., comforting); AND warn before touching
 - Use sensory items to reduce anxiety
- PREPARE PATIENT WITH ASD**
 - Explain what is going to happen, how long it will take, and what equipment will be used. Visual schedule and social narrative will help visualize it
 - Give extra for processing
 - Limit the amount of time that a patient is undressed, in a gown, or on a specialized equipment
 - Allow breaks
- PHLEBOTOMY & OTHER INVASIVE TESTS**
 - Order tests only when absolutely necessary
 - Group tests together when possible
 - Use a numbing spray
 - Give something to distract (e.g., a sensory item)
 - Explain what is going to happen and that it is OK (social narrative, visual schedule)
- BODY AWARENESS, PAIN & SENSORY PROCESSING**
 - Patients with ASD may experience challenges with:
 - Discriminating abnormal body sensations;
 - Pinpointing the location of a symptom or type and quality of a sensation (high or low pain thresholds);
 - Recognizing normal stimuli (e.g., hunger, need to urinate)

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Goal Statement

- Identify potential barriers and limitations for establishing awareness about developmental monitoring, early screening, and other evaluations.
- Provide evidence-based information and resources to build awareness across the state about:
 - developmental monitoring, early screening, and other evaluations,
 - benefits of such monitoring, screening, and early interventions,
 - recommended training resources across services and families, and
 - benefits of service coordination across agencies
- Recognize new local and state efforts in implementing monitoring, early screening of ASD and dissemination of knowledge in efforts to establish sustainability and early access across the state.

Action Plan

These steps will help move towards addressing the current goal:

- Identify and share reliable solutions, existing databases, and training resources related to early screening and diagnosis. Target medical students, residents and fellows as well as practicing pediatricians, family physicians, nurse practitioners, physician assistants, and other medical professionals (e.g., via the INformation Network site, newsletter, social media).
- Identify, compile, and share reliable supports for building advocacy and self-advocacy platform for early identification and screening
- Develop awareness of and practical resources for addressing culture, diversity, equity, and inclusion in monitoring and screening of autism spectrum disorder
- Identify and analyze current areas of need in access to resources and services for people with ASD across the lifespan using the Indiana Needs Assessment Survey data collected by HANDS in Autism®.
- Explore the types of information, training and support available to inform choice and use of developmental screens currently used to make recommendations regarding the information and other supports needed for families and providers and shared via the INformation Network.
- Develop a method to work with and engage IIACC members and the Indiana community at large to share resources and best practices via the INformation Network site.
- Inform and regularly update state and local governing agencies and local opinion leaders about ASD-related challenges and areas of need in terms of developmental and diagnostic screening.

Sample Products



Infocards and screening info posters

GOAL 4

Access to All Needed ASD Health, Mental, Education & Social Services



Goal Statement

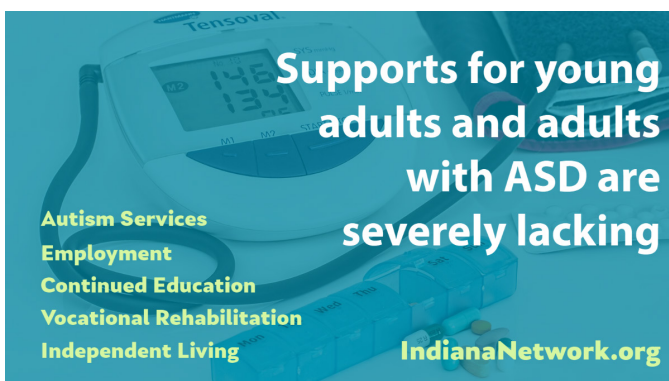
- Build awareness about and importance of health, mental health, educational, and social services on the local and state levels
- Promote blended comprehensive care across services and lifespan focused on preferences, values and needs of people with ASD.
- Support advocacy and self-advocacy through awareness building, access to training, support and resources.

Action Plan

The following steps will help movement to support the current goal:

- Identify and categorize types of needs, consumer/learner profiles, resources, and access across health, mental, education, and social services that could be accessed across the lifespan (via INformation Network and the Indiana Needs Assessment collected by HANDS in Autism®)
- Identify, compile, and share practical supports for building an advocacy and self-advocacy platform for accessing diverse services across the lifespan
- Identify practical resources and supports to address social and family issues surrounding mental health, services, and the stress it puts onto the family and rural/urban community; share via the INformation Network site and social media
- Identify and offer practical resources and organizations that may support the needs of professionals and individuals with ASD seeking access to services, including but not limited to current databases, associations, and governmental agencies
- Inform and regularly update state and local governing agencies and local opinion leaders about ASD-related challenges, needs, and areas of need in access to services.

Sample Products



Infocards and goal-relevant promos



Successful Youth Transition to Adult Services, Work & Independence within Inclusive Communities

GOAL 5

Goal Statement

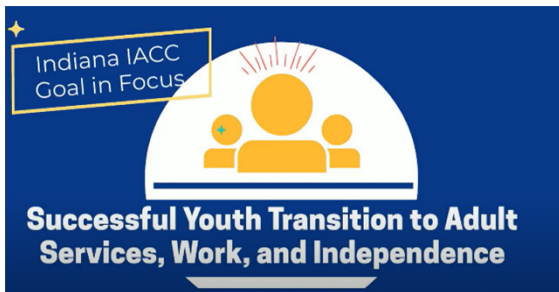
- Improve readiness for successful transition, adaptability, and mobility among transition services by building awareness of:
 - ASD in adulthood and
 - core areas of transition planning.
- Support local, regional, and state efforts in promoting awareness about:
 - transition to adulthood
 - needed community support
 - needed supports for successful inclusion and access of young adults with ASD into the community.

Action Plan

The following steps will help movement to support the current goal:

- Identify areas of need in types of resources and access to transition services across lifespan using the Indiana Needs Assessment conducted by HANDS in Autism®
- Identify a common standard of information, training and support regarding choice and use of transition services and strategies to share via the INformation Network.
- Engage IIACC members, regional community advisory groups (e.g., LCC network), and the Indiana community in disseminating resources on transition
- Identify, compile, and share practical supports for building advocacy and self-advocacy platform for transition planning, employment, and access to vocation training and resources
- Inform and regularly update state and local governing agencies and local opinion leaders about gaps and needs in terms of services and supports needed for successful transition to adulthood in ASD
- Promote efforts of self-advocacy through awareness building, access to training and resources, and other opportunities.

Sample Products



Informational cards, handout, video and goal-relevant promos

Individuals with ASD are attentive, focused, and reliable employees

INDIANANETWORK.ORG

INDIANA INTERAGENCY AUTISM COORDINATING COUNCIL (IIACC)

disABILITY EMPLOYMENT Awareness Month

OCTOBER 2021

Indiana Interagency Autism Coordinating Council (IIACC) IndianaNetwork.org

TRANSITION TO ADULTHOOD

DEFINITION OF TRANSITION AGE

The definition of "transition age" varies but is typically viewed to range from mid adolescence (e.g., ages 14- or earlier for more positive outcomes; to 18) through young adulthood (e.g., ages 24 to 26). This period encompasses most of high school, postsecondary education and training, as well as securing and retaining employment and moving towards independent living (Department of Health and Human Services, 2017).

TRANSITION IN NUMBERS

The current landscape for transition-aged individuals with ASD is bleak, but improvements are possible.

- 20% currently require full-time care/adult day (Taylor & Seltzer, 2012)
- 56% currently require full-time care/adult day (Taylor & Seltzer, 2012)
- 42% employment gap for individuals with disabilities in Indiana (2021 Unified State Plan, v3)
- <50% engaged in community activities or events (HANDS in Autism® Needs Assessment)
- <80% have limited or no access to transition planning (HANDS in Autism® Needs Assessment)

INDIANA AUTISM NEEDS ASSESSMENT

Survey Respondents: 43.8% (Urban), 25.8% (Rural), 24.4% (Mixed)

Survey Respondents	Indiana Census	US Census
African American	5.2%	12.3%
Asian/Pacific Islander	0.3%	5.5%
Hispanic/Latino	10.1%	18.3%
White	84.4%	63.9%
Native American	0.7%	1.2%

HELPING TO ADDRESS COMMUNITY-INFORMED STATE PRIORITIES

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GOAL 6

Adequate Equitable Access to Resources, Funding, Inclusive Community & Basic Living Conditions to Meet Quality of Life Outcomes



Goal Statement

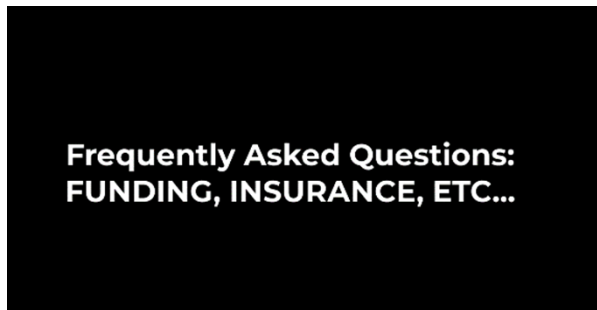
- Recognize the need for equitable (fair and impartial) access to resources, funds and living conditions.
- Assess current barriers and needs in order to access adequate equitable resources, funding, and basic living conditions to meet person's vision for a good life.

Action Plan

The following steps will help movement to support the current goal:

- Identify current challenges and areas of need experienced by individuals with ASD and families in terms of accessing resources, housing, funding, and other services
- Identify, compile, and share practical supports for building advocacy and self-advocacy platform for access to housing, funding, insurance, and other aspects of basic living that improve quality of life
- Identify practical strategies, options, and resources on housing, funding, and services of entitlement and share via the INformation Network site and social media
- Inform and regularly update state and local governing agencies and local opinion leaders about ASD-related challenges and areas of need experienced by individuals with ASD and their families in terms of equitable access to resources and supports across the lifespan.
- Promote efforts of self-advocacy through awareness building, access to training and resources, and other opportunities.

Sample Products



Informational & Resource Videos



Goal Statement

- Provide access to evidence-based and best practice tools, resources, and training to improve:
 - field-based awareness and recognition of ASD
 - use of tools to support identification, interaction and reporting among justice and public safety personnel and settings.
- Support efforts aimed at building empathy and remove implicit bias in order to provide individuals with ASD with equitable and unbiased treatment.
- Promote efforts of self-advocacy through awareness building, access to training and resources, and other opportunities.

Action Plan

The following steps will help movement to support the current goal:

- Identify current standards and availability of resources to build awareness, model strategies, and promote change among law enforcement, frontline workers, first responders, and justice personnel
- Identify, compile, and share practical supports for building advocacy and self-advocacy platform for events when needing to engage with law enforcement
- Identify resources and practical supports/strategies on awareness and skill building and training of first responders and justice system employees; and share via the INformation Network site and social media
- Identify current challenges and areas of need experienced by justice system employees, individuals with ASD and families across the lifespan to inform awareness and training materials and resources
- Highlight and share such resources and materials using social media and newsletters (e.g., IIACC newsletter, Facebook)
- Identify a standard set of information, training, and support regarding challenges of individuals with ASD that may lead to the increase in the frequency of interactions with first responders and the justice system to be shared via the INformation Network.
- In collaboration with regional and local advisory groups (e.g., LCC network), identify and disseminate standard information to build awareness about ASD across first responders and justice system employees
- Inform and regularly update state and local governing agencies and local opinion leaders about ASD-related challenges and areas of need experienced by justice system employees, individuals with ASD and families across lifespan

Sample Products

INDIANA AUTISM NEEDS ASSESSMENT: FOCUS ON STATEWIDE PRIORITIES

JUSTICE & AUTISM (ASD)
Background to the IIACC Research Data Exploration & Application for Solutions

Data to Assist:

- Staying abreast of the current state of the state
- Promoting awareness & intervention
- Distribution of services and funds
- Service coordination & access
- Training options
- Policy & legislation planning
- Support resource sharing
- Early identification
- Disparity considerations
- Research opportunities
- Informing cost differences & funds

INDIANA AUTISM NEEDS ASSESSMENT
Since 2012, over 4,000 Indiana residents (English and Spanish-speaking) across all 92 counties have responded regarding their needs:

- Individuals with ASD
- Families
- Educators
- Healthcare personnel
- First responders
- Justice and law enforcement
- Other service providers

SAMPLE RESPONSE CATEGORIES:
Responses by Region Types* (% of those surveyed)

Urban (50-100k)	Rural (10-50k)	Midwest (60-100k)
43.5%	25.1%	24.4%

* Legally representative of the types of region compared to census data in Indiana statewide

Responses by Race* (% engaged to recent RI and US Census)

Survey Respondents	Indiana Census	US Census	
African American	5.2%	9.7%	13.3%
Asian/Pacific Islander	0.9%	2.2%	5.6%
Caucasian	89.0%	86.6%	81.3%
Latino/Hispanic	4.9%	6.8%	17.8%
Native American	0.9%	0.4%	1.3%

Other Select Variables Available:

- Education level
- Household income
- Family role
- Service access
- Costs & insurance
- Diagnosis

BACKGROUND INFORMATION:

- Individuals with ASD are 7 times more likely to interact with the criminal justice system, either as victims or offenders themselves.
- 13.5% of youth with ASD have been stopped and questioned by police by the time they reached their early 20s. Others nearly 5% were subsequently arrested (New Institute, New York, 2017).
- 16% the prevalence of actual or alleged use of force by individuals with ASD is currently not accurately tracked.
- Socio-emotional challenges present in ASD do not allow individuals to take on stress to peacefully handle the person.
- Presence of comorbid psychiatric disorders can be a strong underlying reason for offensive behaviors.
- 20% of children with autism have been physically or sexually abused. However, justice personnel is not sufficiently ready to protect and advocate for these victims in juvenile courts.

DEPARTMENT OF JUSTICE HIGHLIGHTS (2015):

- 10.5% of state and federal prisoners have cognitive disabilities (ASD, e.g., autism, Down syndrome).
- 11% of prisoners and 20.9% of jail inmates have CD.
- 23% of prisoners and 47% of jail inmates with a cognitive disability reported a 30-day serious psychological distress, compared to 13% of prisoners and 20.9% of jail inmates with a disability other than cognitive.

ASD is not easily recognized by police and other officials, therefore their behaviors may seem able to those of offenders. Challenges with problem solving, acquiescence, lack of understanding of the events, and stress caused by the lights, behaviors of others, and broken routine can cause further aggression or persistence of aggression (Woolsey-Smith & Owen, 2014). In turn, courts often do not accept expert testimony about ASD (King & Murphy, 2016).

DISABILITIES RESULTING FROM ASD:

- Behaviors may be construed as intentional or understanding of intent.
- Comprehending verbal and non-verbal communication.
- High IQ may prevent execution of legal strategy plans.
- Lack of empathy and repeated behaviors may appear to be intentional.
- Poor problem solving ability may reflect on lacking moral values or conscience.

Highlights from Indiana Needs Assessment:

- 12.2% reported police being called
- 2.2% reported police warning being issued
- 1.1% served time in juvenile detention facility

Additionally, funding, time, and practical information were reported by justice personnel as barriers to implementation of best practices in involvement with justice system.

Indiana IACC Goal in Focus

Justice System and Public Safety

Informational Handouts and Videos

HELPING TO ADDRESS COMMUNITY-INFORMED STATEWIDE PRIORITIES

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INFORMATIONAL TRAINING & RESOURCE CENTER

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Join IIACC to be part of the solution!

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GOAL 8 Culturally Responsive Implementation



Goal Statement

- Explore disaggregated national, state, and local data and research to explore cultural differences in ASD diagnoses and services.
- Ensure proportional representation in state and local groups and activities to identify barriers and build awareness about the impact of implicit biases and lack of understanding of differences and commonalities on screening, treatment, education, housing, funding, and other access to equitable resources; as well as how to address them on a local, regional, and state levels.
- Promote efforts of self-advocacy through awareness building, access to training and resources, and other opportunities.

Action Plan

The following steps will help movement to support the current goal:

- Identify practical resources, strategies, and supports for awareness building, bias recognition, and skill training regarding cultural responsiveness across settings; and share via the INformation Network site and social media
- Identify, compile, and share practical supports for building advocacy and self-advocacy platform for cultural responsiveness, including but not limited ethnicity, race, differences in socio-economic backgrounds, and other aspects of cultural responsiveness
- Identify current challenges and areas of need in terms of accessibility of resources and cultural responsiveness based on the Indiana Needs Assessment (conducted by HANDS in Autism®), and other statewide and national data
- Identify a standard set of information, training and support regarding to build awareness within communities and across systems to be shared via the INformation Network by providing culturally responsive information and recommendations
- Engage IACC members and the Indiana community in sharing common resources via the INformation Network site.
- Engage culturally diverse organizations in informing the plan and activities, as well as sharing using social media and INformation Network site
- Inform and regularly update state and local governing agencies and local opinion leaders about ASD-related challenges and areas of need in terms of cultural responsiveness.

Sample Products

FOCUS ON STATEWIDE PRIORITIES, INDIANA AUTISM NEEDS ASSESSMENT 20-30% of Latino and African American children receive an ASD diagnosis and intervention services (Autism Speaks, 2014; CDC, 2018).

CULTURAL COMPETENCE OR RESPONSIVENESS

DEFINITION OF CULTURAL COMPETENCE: Understanding and appropriate responses to the unique combination of cultural, linguistic and individual diversity that the professional and client, parent, or family bring to interactions (ASHA, 2017). In education, it refers to as cultural responsiveness and "teaching that empowers students intellectually, socially, emotionally, and politically by using cultural referents to impart knowledge, skills, and attitudes" (Ladson Billings, 1994, p. 382).

DISPARITY: A noticeable and often unfair difference in treatment of people.

CAUSES OF DISPARITY:

- Immigration status
- Accents/ Location of service delivery
- History of previous abuse or trauma
- Lack of data and research
- Physical limitations or disabilities, like autism spectrum disorder (ASD)
- Differences in language use
- Socioeconomic status and conditions
- Racism, prejudice, and social injustice
- Lack of information about available services
- Lacking education
- Segregation and its link to vulnerability
- Lack of diversity in health care providers
- Lack of culturally competent services
- Lack of physicians in rural areas

INDIANA AUTISM NEEDS ASSESSMENT
Since 2012, we have surveyed over 4,000 Indiana residents (English and Spanish-speaking population) to learn about ongoing needs of:

- individuals with autism
- families
- educators
- healthcare professionals
- service providers (e.g., therapists, service workers)
- first responders
- others working with ASD population.

Responses by Region Types*

Urban (≥ 100,000)	49.8%	Rural (≤ 10,000)	25.8%	Mixed (100,000-100,000)	24.4%
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Average (A) and Most Frequent (M) Age of Diagnosis by Race:

A: 8.5	A: 5.8	A: 4.2	A: 3.2
M: 8.5	M: 4	M: 3	M: 3

Survey Respondents by Race:

Survey Respondents	Indiana Census	US Census	
African American	5.2%	5.7%	13.3%
Asian/Pacific Islander	0.2%	2.2%	0.3%
Caucasian	80.2%	65.6%	61.3%
Latino/Hispanic	4.5%	6.8%	17.8%
Native American	0.5%	0.4%	1.3%

Latino/Hispanic: A: 3 M: 3
African American: A: 3 M: 3
Native Americans: A: 3 M: 3
Caucasian: A: 3 M: 3
Asian/Pacific Islander: A: 3 M: 3

HELPING TO ADDRESS COMMUNITY-INFORMED STATEWIDE PRIORITIES

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Informational Handout