

# Communities United for Early Diagnosis of Autism and Related Disabilities

## The Washington State Community Asset Mapping Project

Coordinated by



### THE NEED

In Washington State there is a lack of equitable access to informed and timely early identification and diagnosis of autism in rural and remote communities. The majority of Autism Diagnostic Centers in Washington State are located in large urban areas and are in association with a university medical center or specialized tertiary medical facility. Diagnostic centers located in Western Washington are separated from rural communities in Eastern Washington by the Cascade Mountains and great distance.

### PURPOSE

Community Asset Mapping (CAM) is a pilot project of the Washington State Combating Autism Advisory Council. The goal is to assure that children in rural and underserved communities with suspected Autism Spectrum Disorder (ASD), or other developmental delays, have equitable and timely access to screening and evaluation services for early identification and diagnosis in locations as close to their homes as possible.

### PROJECT OBJECTIVES:

- Strengthen community-based ASD coalitions of families and interdisciplinary professionals living and working together in rural Washington communities
- Inform and train families, child care providers, and professionals in school, mental health and medical settings on evidence-based ASD screening, assessment and intervention strategies
- Increase the number of ASD diagnostic centers in Washington State and reduce the current waitlists for diagnostic services
- Improve timely referral and access to appropriate early intervention services

### PARTICIPANTS

Eight rural Washington State communities participated from February 2009 – August 2011. The pilot communities were selected based on the following criteria:

- Represent a rural community with geographic and ethnic diversity
- Located at some distance from an existing WA State Diagnostic Center
- Self-identified fragmented community systems of communication and services for children with ASD and their families, and a desire to make improvements
- Identified one or more individuals within the community who is a passionate champion for children with developmental disabilities and their families, and willing to serve as the community project coordinator
- Identified as having the capacity to bring together community members from a variety of service areas such as: families, primary medical care, mental health, child care, early intervention, education, public health, migrant council, community colleges, and others

*It all started when your CAM team came over ... The way that you pulled information out of all the community professionals and the people that were there ... was very, very influential in getting us going... It is helpful to have a neutral party do some of that, too; so often times there are agendas.*

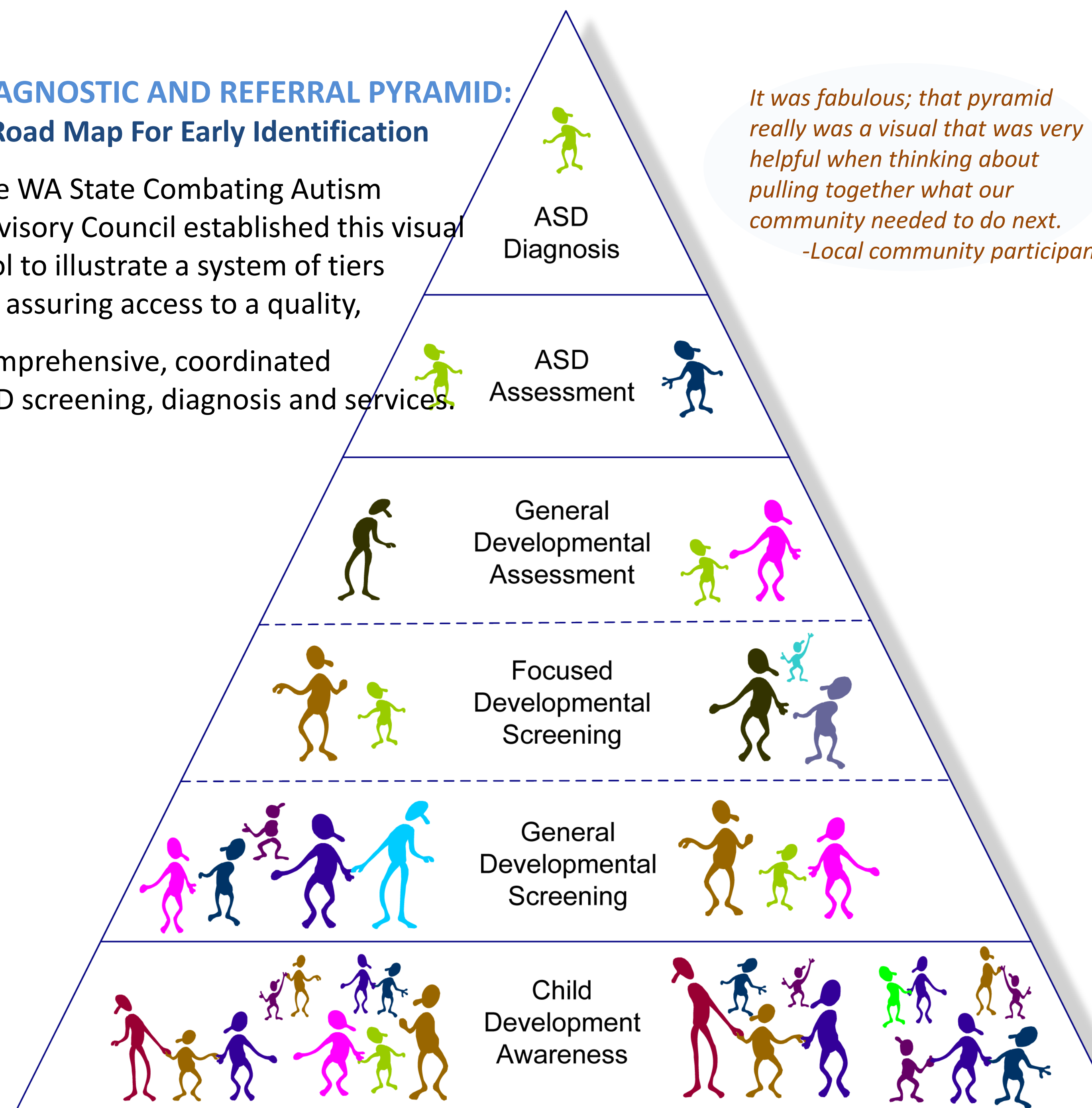
—Local community participant

### Tiers to Autism Diagnosis Pyramid

#### DIAGNOSTIC AND REFERRAL PYRAMID: A Road Map For Early Identification

The WA State Combating Autism Advisory Council established this visual tool to illustrate a system of tiers for assuring access to a quality,

comprehensive, coordinated ASD screening, diagnosis and services.



### METHODOLOGY

Within each pilot community, key stakeholders and families participated in a local onsite community half-day meeting. Meetings were facilitated by staff and faculty from the Washington State Department of Health - CSHCN Program and the University of Washington LEND Program for the purpose of establishing a community-based coalition dedicated to making changes in systems for children with ASD and their families.

Using the “Tiers to Autism Spectrum Diagnosis Pyramid” as an organizing tool, facilitated discussions and brainstorming were conducted with community members to identify the community’s assets, capacity, and gaps in service at each level of the Pyramid.

Each community identified two priorities to work toward to improve the early identification and diagnosis of ASD in their community. Work groups, committees, and a plan of action were established.

Throughout the project communities met on a regular basis to track progress on their plan of action; revisions to the plan were made along the way. Technical assistance was made available by staff from the Department of Health and UW LEND Programs via email, telephone, and in-person visits to the community sites. One of the communities hired a paid facilitator to coordinate their work efforts.

*If [the technical assistance] didn't exist, I wouldn't be doing it ... You need someone who has a bigger picture that you are able to bounce things off of. But at the same time, what's been wonderful is that ... it has been an equal conversation, versus someone saying “this is what we think you should do.” That has been nice.*

—Local community participant

### OUTCOMES:

•**Organizing Framework:** The formal CAM process, utilizing skilled facilitators and the “Tiers to Autism Diagnosis Pyramid”, was a pivotal organizing structure for the local community coalitions. This framework allowed comprehensive community input, and helped narrow down issues to a workable size.

*The CAM structure was helpful as it allowed input from all who chose to participate...It allowed time for discussion but the facilitation kept the session flowing toward results ...The ability to narrow down what seems like an endless topic into a few priority actions was very helpful and I've applied the process to meetings since then.*

—Local community provider

•**Community “Connections”:** These dynamic connections included conversations between communities and others in the state, as well as between individuals and institutions within a community. Local trainings from regional experts occurred to provide a better understanding in each community about evidenced-based ASD screening, assessment, and intervention strategies. The connections also helped inform the larger diagnostic centers of the level of services available in rural communities.

*The helpfulness [of the coalition structure] was that we are building connections with other people in the state – at the universities, institutions, and other organizations...It helps me access resources for the folks in my community. It is fabulous. This has been such an energizing structure and experience in terms of helping us get outside our little silos.* —Local community provider

•**Increased access to a timely diagnosis and services:** Four new regional diagnostic centers are being established in rural communities.

These centers are:

1. Sendan Center -Bellingham, WA
2. Walla Walla School district
3. Island County Autism Screening/Diagnostic Center
4. Lewis County Autism Screening/Diagnostic Center/school & health care combined model

•**Products:**

Participating communities developed a variety of products to enhance ASD diagnosis and intervention services.

