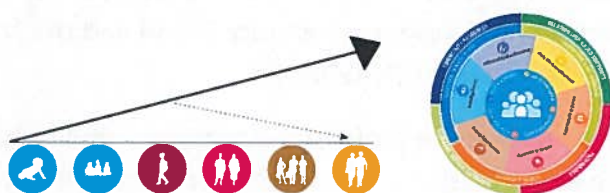


# MARYLAND COMMUNITY OF PRACTICE FOR SUPPORTING FAMILIES

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## The LifeCourse Framework



## Three Year Strategic Plan

October 2017 - September 2020

# Introduction

A Community of Practice is established when multiple people, who share a common concern or goal, strive to learn from each other and engage in practices that lead to furthering their goals in a better way as they interact regularly. A Community of Practice for Supporting Families brings a wide variety of stakeholders together, including people with developmental disabilities and family members, to develop community capacity, bring about changes to policies and practices and to engage in whatever roles they play in a way that better supports families across the lifespan.

Families are the core unit in our society, serving as a source of support for all its members. For people with intellectual and developmental disabilities (I/DD) the role of family is unique, and often central in the support and care provided across the lifespan. There are over 93, 000 Marylander's with developmental disabilities, the majority of whom live within their family homes or are supported by family members. The National Community of Practice for Supporting Families, initiated in 2012, proposed a new structure for implementing supports and services to enhance the lives of families as they support their loved one with I/DD across the lifespan, to lead self-directed, meaningful lives, fully integrated in the community. It is operated under a five year grant awarded to NASDDDS by the Administration on Intellectual and Developmental Disabilities (AIDD) beginning October 2012. Grant partners include University of Missouri Kansas City-Institute on Human Development (UMKC-IHD), Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS).

Since then, the National Community of Practice (CoP) for Supporting Families has expanded its reach to include 17 states that are working to establish communities of practice, with systems and policies to better support families. In 2016, Maryland, along with a growing number of states, joined the National Community of Practice (CoP) for Supporting Families, to better support families of people with intellectual and developmental disabilities (I/DD) across the lifespan, using the LifeCourse Framework. The LifeCourse Framework is the cornerstone of the CoP. Its principles, language and tools were created by families, for families, and people of all abilities to develop a vision for "the Good Life" and to reach it.

The Maryland Community of Practice for Supporting Families, utilizing the LifeCourse Framework (MD CoP) will achieve this through partnerships, policies and programs that seek to build capacity to enhance the lives of families of people with I/DD. Maryland adopts the concept of serving "the All", which includes all Marylanders with I/DD whether or not they are receiving formal services.

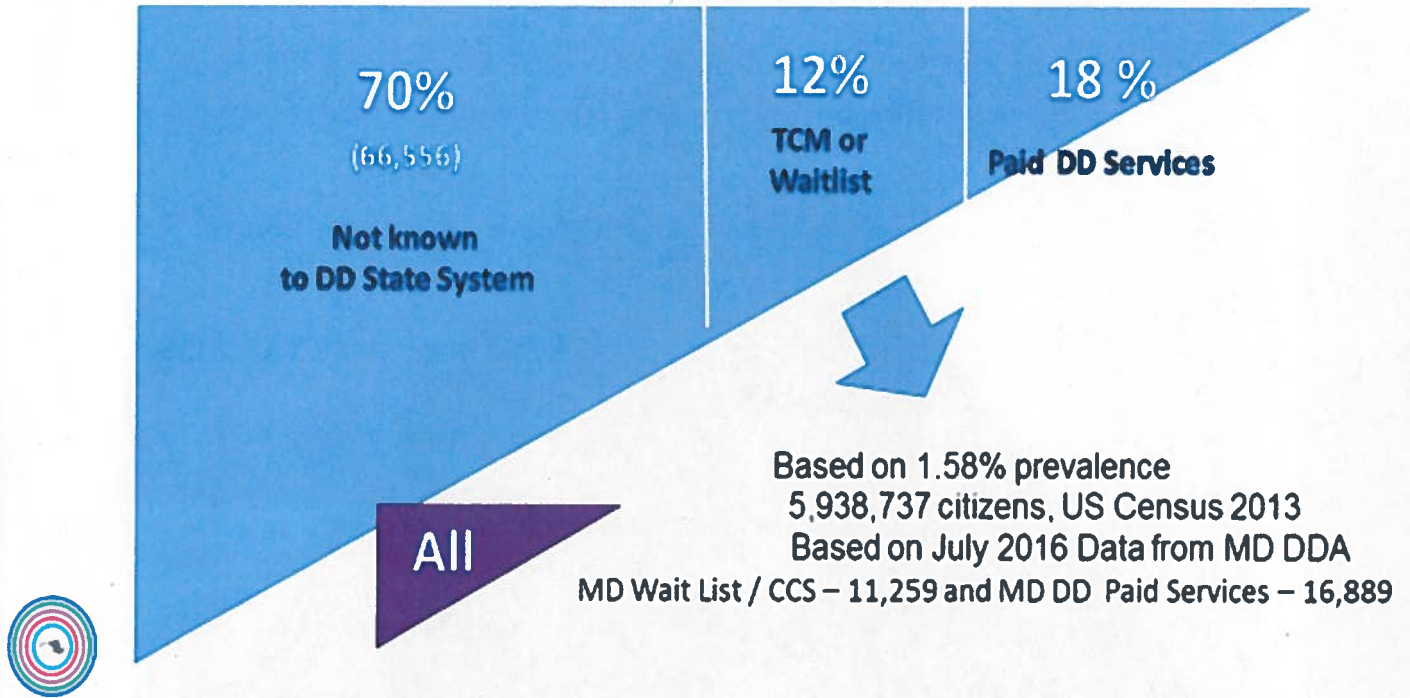
*The overall outcome of supporting families, with all of their complexity, strengths and unique abilities is so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members.*

- AIDD National Agenda on Family Support Conference, 2011



# Marylanders with I/DD

93,830 estimated State with Developmental Disabilities\*

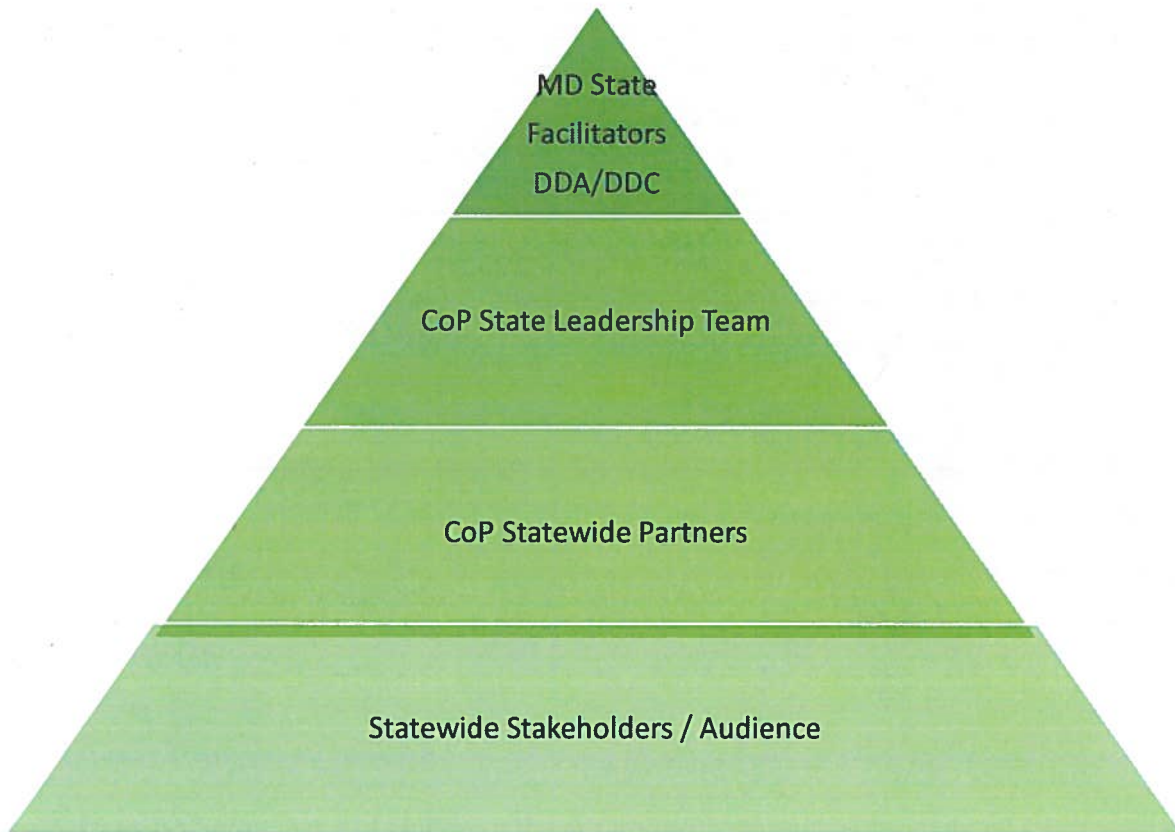


The MD CoP is led by a Leadership Team, representing the partnerships that will determine and affect positive systems change that will better support people with I/DD and their families, across systems, service areas and the community. The MD CoP is all inclusive of a large number of stakeholders, including, but not limited to: Individuals with I/DD, families, health and educational professionals, social workers, faith-based groups, community service providers such as EMS, law enforcement, health departments, higher education and advocacy organizations.

## The Maryland State Leadership Team

Family Members	The Arc Maryland
Individuals with Developmental Disabilities	Office for Genetics and People with Special Health Needs
Maryland Developmental Disabilities Administration	Department of Human Resources
Maryland Developmental Disabilities Council	Maryland State Department of Education
Maryland Department of Disabilities	Special Olympics Maryland
Maryland Department of Aging	Parents Place of Maryland

## Organizational Structure



## Mission & Vision

The Mission of the MD Community of Practice for Supporting Families, utilizing the LifeCourse Framework (hereafter referred to as MD CoP) is to ensure that practices and policies are in place that will keep families and people with intellectual and with developmental disabilities (I/DD) supported and connected within their communities; with employers, support services, and each other in ways that maximize independence and self-determination across the lifespan.


MD CoP envisions a State where families and people with developmental disabilities and their families are informed and supported to lead what they determine to be their Good Life, fully integrated in their communities.

# Maryland's Starting Point

- 93, 830 - Marylanders have I/DD
- 18% - Recieve Paid DD Services
- 12 % - Wait List / Targeted Case Management
- 70% - Unknown to DD System
- 89 % - Live in their own homes or with family (National Data)
- 4 Regions - Central, Eastern, Southern & Western

Beginning in September 2016, MD CoP State Leadership Team has presented five regional Awareness Events across Maryland, with a total of over 215 attendees, representing a broad group of stakeholders. Local partnerships were evident and others began to emerge around shared issues and priorities. Information and feedback gathered at those events have informed this plan, particularly the areas of priority.

Using the LifeCourse Mapping Tool attendees of these events provided information about where families go to get information, connect with others and receive services and supports in their communities. This information is organized using the Three Buckets of the LifeCourse Framework.

	<b>Discovery &amp; Navigation</b>	Where families and individuals with I/DD get information and tools to navigate life.
	<b>Connecting &amp; Networking</b>	Where families and people with I/DD connect with peers and resources to navigate life.
	<b>Goods &amp; Services</b>	Tangible items families and people with I/DD buy and use. Public and private organizations where families and people with I/DD access support.

Where do Maryland families find the resources they need?

### Discovery & Navigation

- 1) Medical: Physicians, nurses, hospitals, specialty health centers etc.
- 2) Early Intervention / Education (Individual Transition Plans)
- 3) Community Organizations (for example, Kennedy Krieger Institute, Parents Place of Maryland and local Arcs)

### Connecting & Networking

- 1) Faith-based groups
- 2) Support groups for parents and caregivers
- 3) Family to family support

### Goods & Services

- 1) DDA Providers
- 2) Rare and Expensive Case Management (REM)
- 3) Kennedy Krieger Institute

Families are the immediate support systems for many Marylanders with developmental disabilities, both in and out of the formal support system. Initiatives such as Employment First and requirements such as the Home and Community Based Settings rule (Center for Medicare and Medicaid Services), mean that people with I/DD will have increased opportunities for choice and inclusion. Maryland is transforming DD service systems with goals of community integration, self-direction and person centered planning. This is the opportune time to ensure that the transformation is part of a larger shift to reach all of Marylanders with I/DD, by developing and enhancing ways to support their families in all stages of life.








## Priority Areas

The top priority indicated by the attendees of the MD CoP Awareness Events was the overall need for information.

People and families lead whole lives made up of specific, connected and integrated domains that are important to a good quality of life. These Life Domains include **daily living** 🏠, **safety and security** 🛡️, **community living** 🏡, **healthy lifestyle** 🧘, **social and spirituality** 👨‍👩‍👧, and **citizenship and advocacy** 🗣️.

Feedback from stakeholders revealed the following broad priority areas. These areas indicate that families continue to lack information, access and funding for supports and services, and experience isolation within their communities. Further discussions demonstrated that issues under these innovation areas differ across the state and underscored the need to establish regional Communities of Practice for a localized focus for systems change.

Priority areas are aligned in the following chart, with their corresponding Life Domain:

	<b>Information:</b> Families want reliable, consistent information on services and supports within the state and the communities in which they live across the lifespan.
	<b>Funding / Access to Services:</b> Individualized services including behavioral supports, specialized therapies, and respite are integral to support the person with I/DD and their families, but often comes at a high cost
	<b>Community Living (transportation, accessible restrooms, community integration):</b> People with I/DD seek an independent and meaningful life with full access to their communities.
	<b>Health &amp; Wellness:</b> Access to comprehensive, family centered, coordinated medical services within the community.
	<b>Disability Awareness:</b> Orientation and information regarding self-determination for all stakeholders. Establish plan for greater accessibility and integration through awareness opportunities among community services and businesses, including potential employers.
	<b>Education:</b> Ensure a variety of post-secondary opportunities to align with the interests of the individual that includes choices that are available to everyone and provide consistent, and better transition planning that considers the person and their family.
	<b>Employment:</b> Customized employment aligned with skills and interest of the individual. Provide education and training to all stakeholders to best support people to be competitively employed.

## Goal

The goal of the MD Community of Practice for Supporting Families is to build capacity in Maryland at the Statewide and local levels to enhance the lives of families and people with disabilities across the lifespan by establishing partnerships, policies, programs, and supports, guided by the LifeCourse framework, principles and tools.



## MD CoP for Supporting Families, Utilizing the LifeCourse Framework



Community of Practice seeks to bring families, people with I/DD and professional as well as community partners together to align in a manner so that whatever services and resources they provide are done in a way that maximizes and enhances those supports for families across the lifespan. This may mean amending policies, practices or systems or creating new ones. It could even result in changes to laws or regulations. It most certainly means that all community members must be represented in discussions to determine what needs to be accomplished, by whom and how in order to bring about a true Community of Practice.

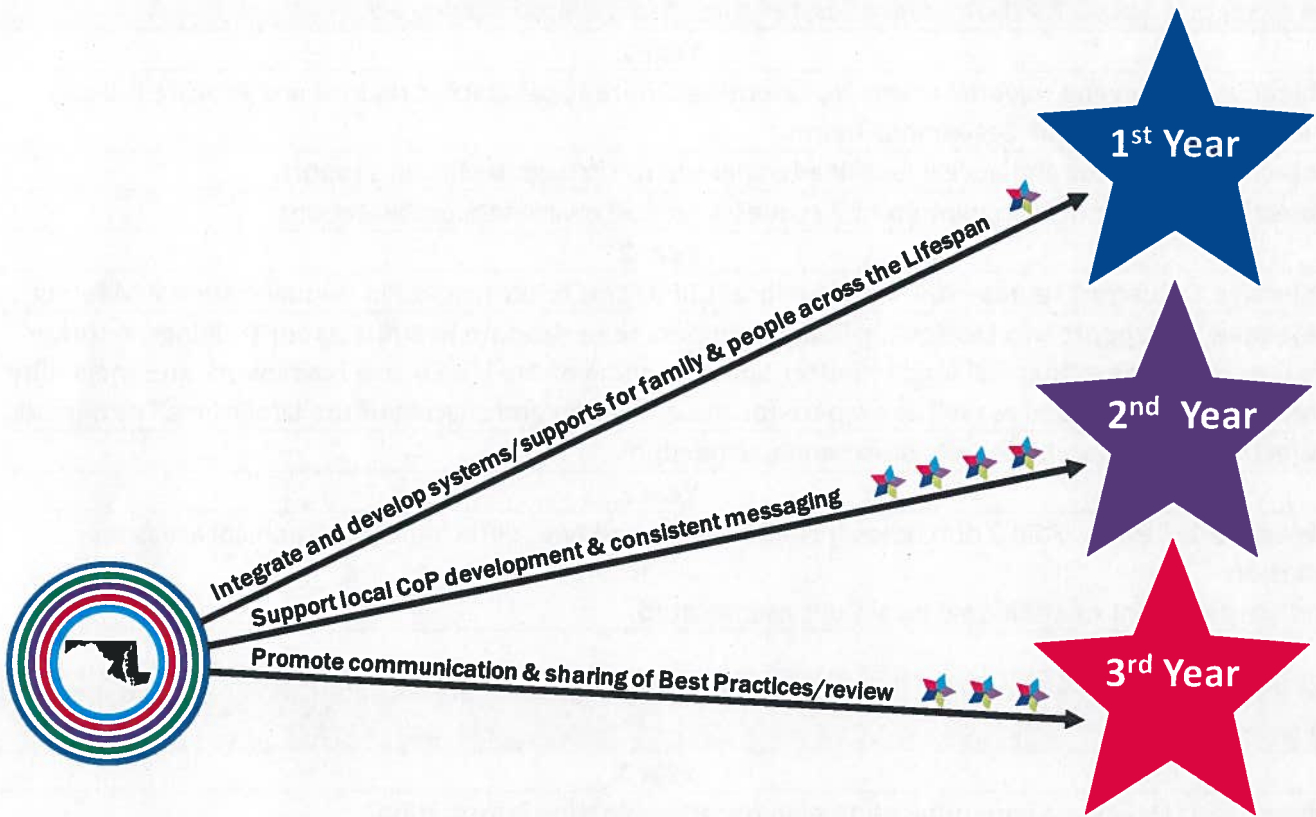
The Life Course Framework provides a common platform for all community members; families, people with DD, public and private agencies, employers, educators and other stakeholders to start from a set of principles that include high expectations for the lives of people with I/DD and acknowledging their fundamental right to live, love, work play and pursue their aspirations – their *Good Life* – fully integrated in their communities.

The LifeCourse Framework further provides a versatile set of planning tools that will serve to guide various stakeholders as they work to form a CoP, by revealing their strengths and needs and how they can fit together, as well as where the gaps are and how to fill them in ways that support families. The tools will also serve to guide self-determination and person centered planning for people and their families; revealing their Good Life and what needs to occur to reach it.





## MD CoP State Leadership Team's 3-Year Plan



The MD CoP State Leadership Team is composed of family members of people with I/DD and people with I/DD, as well as state, local and community stakeholders. These partners work together to support statewide change and local CoPs to better support families across the lifespan. MD CoP State Leadership Team partners will also work within their organizations and agencies to create change that will better support families and promote the use of the LifeCourse Framework.

### **Goals**

**Goal 1:** Integrate current systems and develop systems as needed for supporting families of people with developmental disabilities across the lifespan.

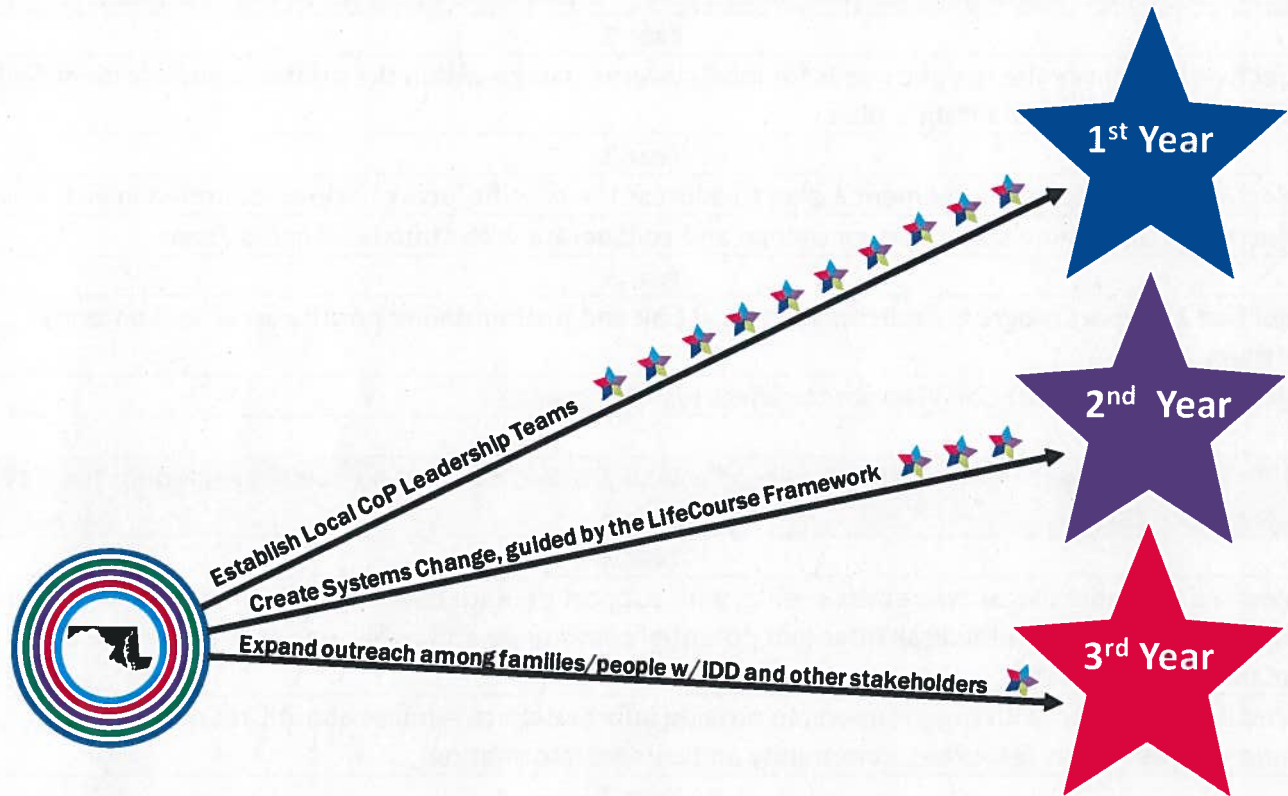
#### **Year 1**

**Objective 1:** Evaluate how state agencies are addressing priority areas to include: the manner in which they

deliver services and their communication with each other and their stakeholders.
<b>Objective 2:</b> Partners will develop agency-based plans to create at least two policy or system changes that will result in supporting families.
<b>Year 2</b>
<b>Objective 1:</b> Ensure consistent messaging about CoP and LifeCourse Principles and tools as well as opportunities to update priorities.
<b>Year 3</b>
<b>Objective 1:</b> Review Goal 1 outcomes from years one and two, determine what systems of support exist, where the gaps are, and what improvements are needed.
<b>Objective 2:</b> Identify new priorities for systems change to better support families
<b>Goal 2:</b> Support Local CoP development and ensure consistent messaging.
<b>Year 1</b>
<b>Objective 1:</b> Convene regional teams representing different geographic regions and Provide full-day orientation for local CoP Leadership Teams
<b>Objective 2:</b> Monitor and advise local leadership teams through technical support.
<b>Objective 3:</b> Respond to minimum of 2 requests for CoP awareness presentations.
<b>Year 2</b>
<b>Objective 1:</b> Support representatives from local CoP teams to participate in Annual National Meeting.
<b>Objective 2:</b> Support two Leadership Team members to participate in ambassador trainings, or other messenger trainings that will lead to better understanding of the LifeCourse Framework and the ability to support local CoP teams as well as prepare for the education and sharing of the LifeCourse Framework.
<b>Objective 3:</b> Support local CoPs to expand partnerships.
<b>Year 3</b>
<b>Objective 1:</b> Review Goal 2 outcomes from years one and two, determine geographical areas for expansion and development of additional local CoPs as indicated.
<b>Goal 3:</b> Promote communication and sharing of best practices with State Leadership Team and among local CoP teams.
<b>Year 1</b>
<b>Objective 1:</b> Develop a communication plan for disseminating information.
<b>Year 2</b>
<b>Objective 1:</b> Host and facilitate an annual event for Regional CoPs to share and learn about best practices to expand efforts to support families.
<b>Objective 2:</b> Produce online presence for MD CoP .
<b>Year 3</b>
<b>Objective 1:</b> Review the work of years one and two, to determine what support systems exist, where the gaps are, and what improvements can be made.
<b>Objective 2:</b> Convene regional teams representing different geographic regions and provide full-day orientation for newly-formed local CoP Leadership Teams.



## MD CoP Local Leadership Team's 3-Year Plan



Local CoP teams will be developed. The first round of local teams will be established regionally (Eastern Western, Central and Southern Maryland). This intends to serve as a starting point. The facilitators and partners will be determined by local stakeholders and with support from the MD CoP State Leadership Team. Although these are not DDA-led or sponsored teams, local teams are encouraged to engage regional DDA staff; specifically to connect with DDA regional directors of Self Advocacy and Coordinators of Family Supports. With the support of the MD CoP State Leadership Team, local CoPs will address and expand upon, the priorities that have been identified through the Awareness Events. These priorities may have significance or approaches that will be unique to specific regions.

### Goals

<b>Goal 1:</b> Establish local CoP leadership teams.
<b>Year 1</b>
<b>Objective 1:</b> Engage with families and people with I/DD, along with other local partners to gain participation on CoP team.

<b>Objective 2:</b> Participate in Orientation event with State Leadership Team and establish plan for ongoing communication.
<b>Objective 3:</b> Identify local stakeholders to develop team membership and a plan to communicate regularly.
<b>Year 2</b>
<b>Objective 1:</b> Refine local priorities and create systems change to better support families.
<b>Year 3</b>
<b>Objective 1:</b> Evaluate current Leadership team and expand to include new partners.
<b>Goal 2:</b> Create Systems change, guided by the LifeCourse Framework, to better support families.
<b>Year 1</b>
<b>Objective 1:</b> Identify the specific needs for local systems change within the priorities already identified and begin to draft an implementation plan.
<b>Year 2</b>
<b>Objective 1:</b> Develop and implement a plan to address the specific local priorities identified in year one.
<b>Objective 2:</b> Determine area of policy change and collaborate with State Leadership Team.
<b>Year 3</b>
<b>Objective 1:</b> Report progress / outcomes to local CoP and further define priority areas and potential partners
<b>Objective 2:</b> Update MD CoP Website to reflect systems change
<b>Goal 3:</b> Expand outreach among families, people with DD and other stakeholders regarding the CoP and LifeCourse Framework.
<b>Year 1</b>
<b>Objective 1:</b> Conduct local awareness events, with support of State Leadership Team, to inform families, people with developmental disabilities and potential community and public partners about CoP and LifeCourse Framework.
<b>Objective 2:</b> Partner with organizations to provide information to families about LifeCourse Framework as well as resources, community and current information.
<b>Year 2</b>
<b>Objective 1:</b> Support at least two local CoP team members to participate in ambassador trainings, or other training that will lead to better understanding of the LifeCourse Framework and the ability to support local CoP teams as well as prepare for the education and sharing of the LifeCourse Framework.
<b>Year 3</b>
<b>Objective 1:</b> Review the work of years one and two, to determine how best to continue to provide information and support in the use of the LifeCourse Framework. Ask what support systems exist, where the gaps are and what improvements can be made.