

Summary of Stakeholder Input Meetings 2018-19

The Alabama Department of Mental Health Division of Developmental Disabilities (DDD) held stakeholder meetings in all five (5) regions of the state to garner information from waiver service providers, families of persons served through the DDD waivers, persons on the waiver, families and persons on the waiting list for services and advocates about changes in existing services and/or additional services that would better meet individual needs. Information about the meetings - the dates, locations and times - were placed on the ADMH website and an informational flyer was distributed across the state that also included a link to an on-line survey.

The information was also shared via the department's Facebook page to solicit input from the public. The on-line survey included the same four questions listed below and asked the person completing the survey to identify themselves as family, person with IDD or provider.

Participation in the Stakeholder meetings and the on-line survey is as follows:

- **Montgomery – Statewide Stakeholder meeting – December 20, 2018:**
19 = Families/Self-Advocates 14 = Providers
- **Region 1 Huntsville – February 27, 2019:** 15 = Families/Self-Advocates 16 = Providers
- **Region 2 Tuscaloosa– March 6, 2019:** 19 = Families/Self-Advocates 37 = Providers
- **Region 3 Mobile – March 27, 2019:**
36 = Families/Self-Advocates/Other Participants, i.e., employees 50 = Providers
- **Region 4 Montgomery – March 13, 2019:** 9 = Families/Self-Advocates 19 = Providers
- **Region 5 Birmingham – April 3, 2019:** 23 = Families/Self-Advocates 42 = Providers
- **On-line Surveys:** 88 = Families 5 = Individual 19 = Advocate 13 = Provider

A total of two-hundred ninety-nine (299) persons attended the stakeholder meetings. One hundred and twenty-one (121) were families and/or individuals served. One hundred seventy-eight (178) were providers. Advocates attended either session and are also included in the total count. There was one-hundred twenty-four (125) responses to the on-line survey and those were identified as follows: Families – 88, Individual – 5, Advocate – 19, Provider – 13.

The December 20, 2019 meeting was facilitated by Dr. Lisa Mills, ADMH consultant. This meeting was held from 10:00 – 2:00 pm and included stakeholders, family, people with both – intellectual and developmental – disabilities and providers, from across the state. Dr. Mills presented a PowerPoint presentation then facilitated conversation about the group. The PowerPoint included National data on LTSS expenditures, challenges Alabama faces based on information published in the UCP report “*the Case for Inclusion*” and other challenges, such as, Reaching People in Need, Promoting Productivity, and Keeping Families together was presented to the groups. It also included a quick summary of Alabama's HCBS waiver spending by service type for the services currently utilized most on the Intellectually Disability waiver such as Residential Habilitation (77.5% of waiver expenditures), Day Habilitation (12.4%) and Personal Care (4.4%). Other services, Supported Employment, Community Experience, Prevocational Services and Benefits and Career Counseling represent less than 1% of waiver expenditures. The PowerPoint was used for all following stakeholder meetings.

The format of the February – April Stakeholder engagements was consistent by group session throughout the state. Invitations were sent to Providers, Advocates, Families of Participants and Families of those on the waiting list for services. Two sessions were held at each of the location. The first meeting was held from 10:00AM to 12:00 AM was specifically for providers. The next session held

from 1:00PM to 3:00PM was specifically for families and individuals. Attendees signed in for each session at each location statewide. Advocates could attend either session. Meetings began with Associate Commissioner T. Pezent asking members to introduce themselves to the others and indicate his/her goal for the day. The Associate Commissioner then began the presentation with basic information about the HCBS Settings Rule requirements for providers receiving HCBS funding and preceded with Dr. Mills slide deck previously referenced.

Associate Commissioner Pezent then explained about ADMH desire to develop an 1115 waiver designed to assist the state in containing costs, increase employment, reduce the waiting list, keep families together, right size services, provide an adequate network of providers in all areas of the state and provide an adequate and quality direct service workforce, in addition to, complying with the HCBS Settings Rule. She further explained that improved Person-Centered Planning, Creating Conflict Free Case Management, and improved monitoring of service providers will all work together to ensure ongoing compliance with the rule.

After the PowerPoint presentation, Ms. Coffey, worked with persons attending each session. Attendees were put into small groups and each group asked to choose a recorder. The groups were provided the questions and instructed to 1) discuss among themselves in the group with the recorder taking down all responses. Once the responses were completed, the group was to decide their three (3) most important responses and rank them in order of importance with one being the most and three the least.

Questions were posed one at a time. Ample time was provided for group discussions by questions. The questions are:

- 1) What type of services do people with ID/D need?
- 2) If a person with ID/D lives in the home with family, what kinds of supports do the family caregivers need?
- 3) How can services for ID/D be improved?
- 4) How can services to ID/D be more cost effectively so that more persons who need services receive them?

Each group was asked to record their top three priorities (additional priorities were accepted) to each question on wall mounted note pads organized by question. Once all groups recorded their priorities, Associate Commissioner Pezent reviewed the lists with all participants beginning with question number one. Questions were posed to stakeholders for clarification of priorities as needed. Responses were recorded by Ms. Pezent on the same note pad listing priorities. Some responses prompted a large group discussion from which more information from stakeholders was obtained. Ms. Coffey made notes during the review of the responses.

All information from the December 20 and February – April meetings were reviewed for frequency of similar responses within each group and categorized by providers and families/advocates. Then, those responses were reviewed for final unduplicated results. Information from the online surveys were included in Part II of the summary below. See the following pages for summary of the results of stakeholder engagement meetings and on-line surveys. Page 6 and 7 are unduplicated results.

December 20, 2018 Stakeholder Meeting – unduplicated

(NOTE: This is summary of most frequent and consistent comments and feedback)

<ul style="list-style-type: none"> • No wait List • Transition services • Employment services • Person Centered Plans • Family education about waivers, services and how to navigate them, system to complicated to understand • Self-directed services • Nursing care services • Companion services • Services for deaf/blind • Needs assessment/comprehensive first point of contact that helps plan all aspects of life • Technology-Resources Specialist, smart home technology • More integrated housing options • Integration, not segregation • De-institutionalize services, define restriction • Certification presents barrier, limits change • Need more independent living as in past • Less complex system • (using) Criticality (for waitlist) presents a barrier • Flexible, health care agencies braiding services • Outcomes based not service based services to support families • Preliminary PCP • More input from families • Case Management for waiting list • Affordable housing • Less restrictive housing and visibility – co-housing integrated (Arizona and Oregon concept) • Better evaluation of support needs and determining their vision for a good life • Flexible services so that people can use them in different ways • There are complexity and so many rules for services, eligibility for waivers. • Meaningful individualize planning is a must, more participation in PCP meetings • Need policy and procedures, need waivers in writing and on tape (case managers read information to individuals. • Need information campaign, email, flyers, website, and etc. Include schools, case managers, and complimentary training to families. 	<ul style="list-style-type: none"> • We need to educate the consumers • Educate teachers about DD services and training for families and individuals. • Advocates for individuals (that) don't have families who to advocate for them • Close the front door on some stuff like day habilitation. • When the institutions were closed, a lot of group homes were opened in a hurry. • Need outcome-based incentives • Project search • Transportation services • Personal care services • Service brokerage services • Need to know how self-directed works • Help people to manage budget and navigate self – directed services • There is not effective work toward technology. A resource Specialist is needed to work with case managers for technology. • Self-directed services rules limit all services • Infrastructure limits services • Delivery System of people to train parents/support and educate parents • Before putting individuals on the waiting list see screening of what type of services individuals need • Assessment for services and identifying services • Screen family for what they need and link for other services. • More stakeholder engagement for help at the local level, include schools, training, and webinars. • Case Manager should have quarterly meetings for information gathering. • Better assessments/screen people for alternative eservices, and case managers should prioritize employment. • Showcasing examples of success • Increase capacity of Services • Waiver transparent/user friendly • Staff Provider facilitation of “choice” • Control over resource • Broader Employment Expectations • Employer investment • Community experience • Education, from birth to death • Communication about needs-based services
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February – April, 2019 Stakeholder Meeting Summary

(NOTE: This is summary of most frequent and consistent comments and feedback.)

Question	Most frequent responses	Other responses
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<i>(P)rovider (F)amily</i>		
PQ1: What are the kinds of HCBS do people with IDD need most?	<ul style="list-style-type: none"> • Transportation • Employment • Financial Education • Resource Education • In-home supports • Respite 	<ul style="list-style-type: none"> • Community Integrated Services • Supports for aging population • Transition service – youth to adult • Crisis Intervention service (in/out of home)
PQ2: If a person with ID/DD lives at home with family, what are the kinds of supports does the family caregiver need?	<ul style="list-style-type: none"> • Transportation • Rural Transportation • Respite • Family education (available service) • Personal Care 	<ul style="list-style-type: none"> • Employment • Self-directed options • Adaptive equip/supplies • Nursing (in-home) • Case Mgmt Service
PQ3: What are the kinds of ways that services for people with IDD receive can be improved?	<ul style="list-style-type: none"> • Family/Individual education about service options • Dental • Employment (self-employment) • Flexible service as needs change 	<ul style="list-style-type: none"> • Crisis stabilization • Personal Care • Community experience service (weekend 3:1 option other than 1:1 PC) • Self-directed options • Health homes • Transportation • Value based Funding model • No wait list • Independent Living Options
PQ4: What are the ways to provide HCBS to persons with IDD more cost effectively so that more people who need services can receive them?	<ul style="list-style-type: none"> • Serve less critical earlier (no criticality waitlist) • Better needs assessments (to right size supports) • Assistive technology • In-home service • Transportation • Supported Employment 	<ul style="list-style-type: none"> • Utilize community resources (churches, non-profits, etc.) • Family education about service • Bundling Services • Respite • Crisis Services • Independent Living options (transition from Residential Hab) • Self-directed options • Transition service
FQ1: What are the kinds of HCBS do people with IDD need most?	<ul style="list-style-type: none"> • Employment • Self-directed service • Personal care • Transportation • Family Education (changing needs related to diagnosis) • Day services for socialization/day programs • Assistive technology • In-home modification • Skilled nursing in-home • Peer to Peer support • Support Network Resource (vetted Staff List for in-home supports) • Crisis Intervention/Behavioral Support service (including in-home) • Independent living skills training • Therapies 	<ul style="list-style-type: none"> • Sign language • Transition service • No wait lists • Home maker services • Personal Emergency Response Service • Special Medical Supplies • Nutrition counseling

	<ul style="list-style-type: none"> • Housing opt/supported living (Aging caregivers who can no longer provide care) • Case Mgmt • Self-Directed Employment Service Option • Serve Developmental Disability population (not just ID) • Family Counseling/Therapy • Family education (financial planning guidance) 	
<p>FQ2: If a person with IDD lives at home with family, what are the kinds of supports does the family caregiver need</p>	<ul style="list-style-type: none"> • Respite service (including emergency respite) • Family education (recognizing needs/abilities, navigating service system, life skill supports, community supports options) • Crisis Intervention/Behavior support (including ABA) • Transportation • Self-Directed services • Employment • Personal Care and Personal Care with travel • Day service for socialization • Therapies (OT, PT, ST) • Support Network Resource (SD/In-home staff) • Accessible Housing (Assistive Technology) • Bundle Services • Resource Center (education about resources) 	<ul style="list-style-type: none"> • Family education/counseling • Peer to Peer • Continuity care • Whole person/trauma informed care, not just case management • Housing grants • DD services (not just ID) • Special Med Supplies • Skilled Nursing • Service animals • Case Management • Pay families for care
<p>FQ3: What are the kinds of ways that services that persons with IDD receive can be provided?</p>	<ul style="list-style-type: none"> • Self-Directed Services to include ability to pay overtime, assistive technology, more control, choice in service, and flexibility in implementation, more than one Fiscal Management Services option • Respite • Family (Community) Education (resources, services) • Employment • Independent living specialist • Needs Assessment (right size supports) • End waitlist • Developmental Disability Services, not just ID • More control, choice for service and flexibility • Services for adults with autism • Care coordination, not just CM • Higher rates for providers to recruit better employees and reduce turnover (continuity of supports), qualified, trained employees • Personal Care providers (lack of access to PC service) 	<ul style="list-style-type: none"> • Behavior supports • More mental health care to include young adults • Therapy for young adults with ID • Peer to Peer mentor for person served • Options for working families (single moms) • Bundled services • Value based funding model • Day service for socialization •

	<ul style="list-style-type: none"> • Increased monitoring/accountability of providers • Transportation (dependable, consistent) • Support Network Resources (Reliable workers) • More in-home services in rural areas; access to service in rural areas • More input from families • Move away from facility based and group home care • 	
<p>FQ4: What are the ways to provide HCBS to persons with IDD more cost effectively so that more people who need services can receive them?</p>	<ul style="list-style-type: none"> • Needs assessments (right size supports) • Supported living options • Support Network Resources (reliable workers) • Transition services • In-home services • Family education (services, what they are, how to manage/access) • Self-directed service., more FMS options, flexible spending • Assistive technology • DD services (to include autism services/ABA) • Reduce reliance on segregated residential and day programs • Employment services and services for people with the most significant disabilities • Better pay for support staff • Assistive Technology in homes (more use of technology to replace staff visits to homes) • Personal care (accessible) • Allow families to get paid • Respite care (stipends) • Better, more engaged Case Mgmt • No waitlist, serve people earlier 	<ul style="list-style-type: none"> • Bundling services • Case Management services • More family engagement • Increase ratio of PC service more than 1:1 • Financial incentives for best use of funding for best integrated outcomes • Better monitoring and evaluation of services/providers • More mental health service/therapists • Easier process to become a provider/family to become providers

PART II: Summary of services identified through all Stakeholder meetings and on-line survey

<i>Most frequent responses</i>	<i>Other responses</i>
<ul style="list-style-type: none"> • Transportation (dependable, consistent) • Rural Transportation • Employment services • Education: financial, financial planning, resources, service options, access to services, • Respite • In-home supports, Personal Care • Dental • Employment: self-employment, supported employment • Flexible service as needs change • No criticality waitlist, serve people earlier • Assistive technology 	<ul style="list-style-type: none"> • Community Integrated Services • Supports for aging population • Transition service – youth to adult • Crisis Intervention service (in/out of home) • Crisis stabilization • Adaptive equip/supplies • Nursing (in-home) • Case Mgmt Service • Personal care ratio more than 1:1 • Health homes • Independent Living Options (to include transition from Residential Habilitation)
Services identified by families not included above	
<i>Most frequent responses</i>	<i>Other responses</i>
<ul style="list-style-type: none"> • Family Education: changing needs related to diagnosis, recognizing needs/abilities, services, navigating service system, life skill supports, community support options, financial planning guidance • Comprehensive first point of contact that helps plan all aspects of life • Day services for socialization/day programs • In-home modification • Skilled nursing in-home • Peer to Peer support • Support Network Resource to identify and vet reliable workers • Crisis intervention and/or Behavioral Support services (including in-home services, ABA) • Independent living skills training • Therapies (OT/PT/ST) • Housing opt/supported living (Aging caregivers who can no longer provide care) • Case Mgmt • Self-Directed Service: Employment Service Option, ability to pay staff overtime, assistive technology, more control, choice in service, control over budget, education and flexibility in implementation, more than one FMS option, more service brokers • Serve Developmental Disability population (not just ID) • Family Counseling/Therapy • Emergency Respite • Access to Personal Care providers and Personal Care with travel • Accessible housing (Assist Tech) • Supported Living options • Independent living specialist • No waitlist, serve Developmental Disabilities, not just ID. Serve people earlier. Include autism services/ABA 	<ul style="list-style-type: none"> • Sign language • Home maker services • Personal Emergency Response Service • Nutrition Counseling • Family counseling • Housing grants • Special Med Supplies • Service animals • Access to more mental health care to include young adults • Therapy for young adults with ID • Technology-Resource Specialist, smart home technology • More integrated housing options • Less restrictive housing and visibility – co-housing integrated (Arizona and Oregon concept) • More independent living • Case Management for waitlist • Service brokerage services

<ul style="list-style-type: none"> • More control, choice for service and flexibility • Services for adults with autism • Care coordination, not just CM • Higher rates for providers to recruit better employees and reduce turnover (continuity of supports), qualified, trained employees • Personal Care providers (lack of access to PC service) • More in-home services in rural areas; access to service in rural areas • More input from families • Move away from facility based and group home care • Transition services • Employment for people with the most significant disabilities 	
<i>Other frequent comments</i>	
<ul style="list-style-type: none"> • Improved needs assessments • Bundling of services • Easier access to list of available services statewide • Reduce reliance on segregated residential and day programs • Better pay for support staff • Allow families to get paid • Better, more engaged Case Mgmt. • Value based funding model; Financial incentives for best use of funding for best integrated outcomes • Whole person/trauma informed care, not just case management (Mississippi?) • Continuity care • Pay families for care • Options for working families (single parents) • More family engagement (to tell what their needs are) Better monitoring and evaluation of services/providers 	<ul style="list-style-type: none"> • Easier process to become a provider/for family to become providers • Constant training for direct (care) and service providers • Less complex system • Integration, not segregation • De-institutionalize services, define restriction • Improved Person-Centered Planning • Increased monitoring/accountability of providers