



PANDEMIC TOLL ON MARYLAND

Higher Costs, Less Revenue, and An Uncertain Future for People with Intellectual and Developmental Disabilities, Their Families, and Community Supports

The Arc was created in the 1950's, out of the wishes and dreams of parents who persisted and created the change they wished to see for their children with intellectual and developmental disabilities (I/DD). Before that time, children with I/DD in Maryland were placed in institutions, denied the right to live, learn, play and worship among peers and family. Today, people with I/DD live and work in all communities across the state, thousands with support from DDA provider organizations like The Arc. They are valuable contributors to the fabric of every community.

People with I/DD and their families require adequate support in order to live full and inclusive lives, and that support comes through DDA provider organizations. **A survey of the ten local chapters of The Arc in Maryland showed startling statistics that point to a pending system-wide breakdown which will leave thousands of people with I/DD at risk—literally stranded with no support services and no available providers.**

- **\$1.88 million** has already been spent on additional overtime, incentive pay, hazard pay and sick leave (page 4)
- **\$409 thousand** has been spent on PPE and cleaning services in just two months (page 3)
- **\$3.8 million** in revenue has been lost because providers are unable to provide and receive funding for essential services (page 6)
- Most providers have **only 1.2 months** of reserve funding reserves remaining, clearly placing them in an unstable position (page 9)
- People with I/DD accessing day supports has **dropped by nearly 50%**, straining providers and family caregivers by requiring additional support hours at home (page 6)
- **63%** of surveyed providers reported people with I/DD experience barriers to remote supports, including lack of technology, lack of skills, and lack of internet service (page 5)

The Arc chapters in Maryland collectively support roughly 30% of the people in the state who receive developmental disabilities services. While thousands of people are the direct beneficiaries of The Arc's services and supports, countless more benefit through programs, events, trainings, information, referrals, and other family support initiatives.

The Arc chapters offer a wide range of support services, including personal care at home, coaching in community jobs, daily living skills training, prevocational and meaningful day activities, residential services and other health supports. Of the 10 "full service" chapters of The Arc in Maryland, eight are considered small businesses, and all 10 serve as economic engines within their communities, providing jobs, health insurance and other benefits to Direct Support Professionals (DSPs), while also supporting people with disabilities and older adults to live and work in their communities, stay healthy, and remain safe.

The Arc chapters across the state recently completed a survey focusing on the overarching impacts of the pandemic, and cost and quality impacts to daytime services for people with I/DD (including supports for employment, day habilitation, retirement, and medical day). Thousands of people throughout the state rely on daytime services and supports in order to work, in varying intensities. Many families of people with disabilities also rely on these services. Without a caregiver to support their adult child between the typical work hours of 8 a.m. and 4 p.m., many parents would be unable to hold their own jobs. The importance of these services to our state economy cannot be overstated.

While the numbers reflected in this report are representative of the 10 chapters of The Arc, we believe the data has much wider applicability and should be viewed as a sample of what is happening more broadly across the state of Maryland in provider organizations funded through the Developmental Disabilities Administration (DDA).

As we enter a period of deep consideration and development of a plan to re-open and recover, the data in this report exposes the true condition of provider organizations and illuminates areas our state leaders must consider for the rebuilding, stabilization, and future health services for people with I/DD. DDA provider organizations do the work of the state, supporting over 17,000 people with I/DD in a variety of community settings. The state has a responsibility to ensure the safety, quality, and viability of DDA community-based system of services and supports.

OVERARCHING CONSIDERATIONS

The COVID-19 pandemic has created unprecedented and unique challenges for DDA organizations in the state. Some organizations indicate they may not survive the pandemic without intervention from the state through funding and policy changes. If left unaddressed, or worse, if budget cuts are instituted for the more than 200 DDA organizations in the state (including the 10 chapters of The Arc surveyed in this report), it is reasonable to assume there will not be enough providers or services to meet the needs of people with I/DD.



Provider business failures were rare occurrences in a pre-pandemic Maryland. In the past, historically larger organizations (The Arc and others) had the infrastructure and reserves to assume the clientele, workforce, and debt of the failing organization. Now, most organizations report they have little operating reserves and with pandemic-related costs, revenue shortfalls, political uncertainty, and resultant “risk aversion,” it is unlikely they would absorb failed providers.

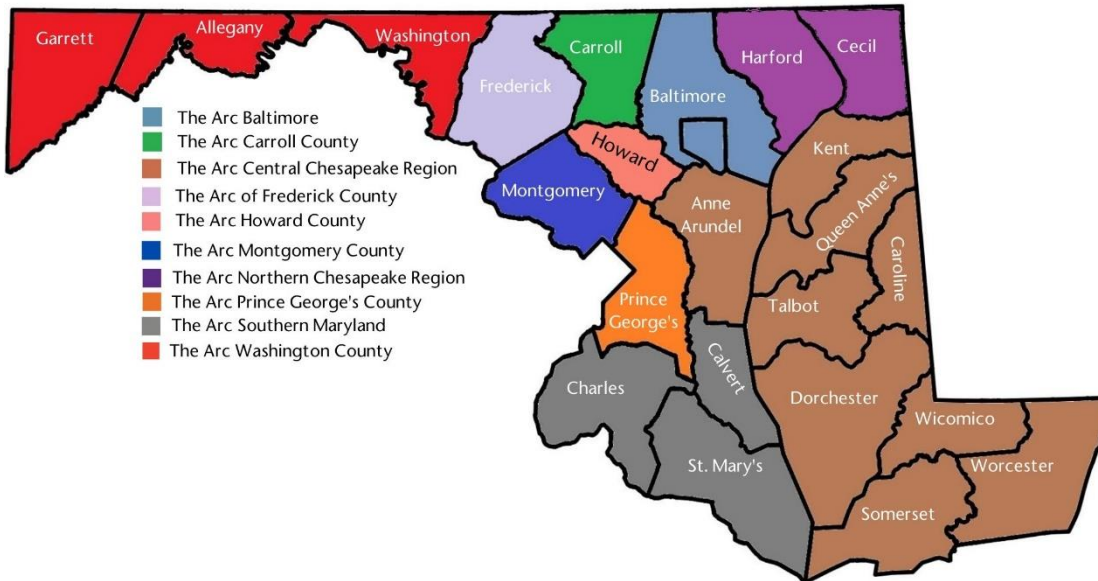
Even the large organizations are not immune from the ravages of the pandemic. What will happen if one of them finds they do not have the resources to operate? Our safety net has been compromised and those organizations which do find a way to survive are expected to curtail their services, leaving thousands of men, women and children with disabilities and their parents without basic, needed services and supports.

SURVEY PARTICIPANTS

All ten of The Arc provider organizations in Maryland participated in the survey. **This network provides direct services and supports to 5,453 people with intellectual and developmental**

disabilities and thousands more family members, children, and adults with disabilities who receive direct services from these organizations but do not have DDA funding for day and employment, residential, camps, family support classes and trainings, respite services, Information and referral services and other supports.

The combined workforce of The Arc organizations exceeds 4,300 employees. Of this number, 88% are front line workers, known as Direct Support Professionals (DSPs).



All 24 Maryland counties, and Baltimore City, are supported by The Arc through direct services or through supportive advocacy and educational opportunities.

SURVEY FINDINGS

ADDED EXPENSES—Significant increases in the costs of doing business



Personal Protective Equipment (PPE) and Additional Cleaning. While DDA provided two “rounds” of PPE to organizations throughout the state, that covered only a fraction of the need for roughly half of the existing providers.

As the state of Maryland prioritized PPE for hospitals and nursing homes, disability support organizations initially could not obtain even basic PPE. Conditions have improved slightly, however The Arc chapters continue to struggle in obtaining hospital masks, gloves, and face shields. Items such as disposable gowns, N95 masks, and shoe coverings are still very difficult to obtain and if available, they can only be purchased at high costs and in limited supplies.

At survey time, only two of The Arc chapters had no positive cases of COVID-19 to date. However, according to the survey, their costs for PPE and additional cleaning supplies were still \$7,500 and \$20,000 respectively. Most of The Arc chapters had at least one positive case of COVID-19, with three chapters experiencing multiple outbreaks. PPE and cleaning supply costs for those organizations ranged from \$25,000 to \$250,000 over a period of two months.

The total cost of PPE and additional cleaning supplies from mid-March to mid-May was \$409,675 for all 10 organizations.



Increased Salary and Pay-Related Expenses. All of The Arc chapters instituted periods of incentive and hazard pay for their front-line workers. This was necessary to properly compensate DSPs working in high-risk health environments, including small congregate group homes.

Some chapters of The Arc were eligible for federal Paycheck Protection Program (PPP) loans from the Small Business Administration. These loans (which may be forgiven in part or in whole) provided funding to offset payroll and operating expenses for a period of up to 8 weeks. The organizations who obtained the PPP used the funding to help maintain their workforce and supplement operating costs, although this relief did not cover their significant DDA revenue losses. Larger chapters of The Arc were not eligible for the PPP program and faced more severe financial consequences than the smaller organizations in the network.

In total, The Arc chapters paid increased overtime, incentive pay, hazard pay, and sick leave benefits costing \$1.88 million in a two-month period. The range was \$72,500 to \$750,000 spent per organization on enhanced essential employee compensation and leave benefits during this period.



Other Expenses. Some of The Arc chapters provide residential group home services to children with developmental disabilities. With schools closed and children kept home, these organizations faced increased costs to cover school-hours support. The Department of Juvenile Services has not provided funding for this expansion of services.

Additionally, several organizations provide after school programs for children with disabilities, and spring and summer camps. One chapter operates three childcare and pre-school programs. The programs are national models of inclusive care; in every classroom, typically-developing children, children with developmental disabilities, and children with special healthcare needs play and learn together.

When Governor Hogan issued Executive Orders to close businesses, The Arc's childcare, pre-school, after school and camp programs ceased to operate, but the fixed costs continued.

They are now at risk as the state re-opens; with social distancing requirements, cleaning needs, and reduced capacity mandates, the programs will not be able to generate enough tuition and fees to cover the heavily increased operating costs. Not only will the situation impact the children enrolled, but there will be broader impacts for hundreds of families who have relied on essential childcare and other services in order to work.

DECREASED REVENUES—Providing community-based services in a closed community



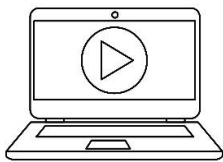
Adult Day Program Closures (as of March 19)ⁱ. Many individuals with I/DD and their DSPs were suddenly faced with a unique challenge—how to provide critical support with no building or community location in which to provide it. Some people who also resided in group homes were able to receive day support in that setting. But many others were suddenly staying at home with their families during day hours, with no (or

limited) paid caregiver support. Aging parents, many with pre-existing conditions, feared exposure to COVID-19 if they allowed paid caregivers into their homes.

Providers of day services were severely hampered, given the current service and setting definitions for Medicaid payment, community closures and stay-at-home orders. *They lost significant revenue as they struggled to keep their workforce employed, with little to no ability to generate revenues to offset their growing operational expenses.*

While some flexibility was eventually created with an emergency amendment to the state's Home and Community Based Services (HCBS) Medicaid Waiver (Appendix K), that waiver amendment was not approved until a full month into the pandemic. Changes to billable service definitions created some opportunities for providers to bill for services in different settings for different units of time, and remote services were approved to allow individuals with disabilities to receive tele-supports.

Some people are thriving with this new way of receiving support, but there is a larger segment of people with I/DD for whom remote services are not a viable alternative to in-person support.



Barriers to Remote Support Services. There are four overlapping barriers for people with I/DD in receiving remote services: lack of technology, lack of internet/phone service, disability-specific barriers, and disinterest in remote service. Individuals who have been unable to participate in remote services report the following issues.

63% reported a lack of technology. Individuals and their families either did not have the needed technology or lacked the skills to properly utilize the technology needed to meaningfully access remote support services.

50% reported a lack of internet/phone service. Either they lived in remote areas of the state or the inner city within a service “dead zone” or they lacked the financial resources to purchase internet service. Internet access is not a service that is currently funded by the DDA. Some families do not even have a telephone through which a provider could provide remote support services.

75% reported the individual's disability was preventing the person from meaningfully participating in remote services.

100% reported the lack of participation was due in part to disinterest in receiving remote services. Families reported that they need in-person assistance and caregiving for their family member and remote support was simply not a service that would effectively replace staff and fulfill their needs.

Some individuals disinterested in receiving remote services stated they were not interested in being on the phone or computer because they truly needed the physical assistance from their DSP. There were also reports by some as a mistrust in technology or fear that they would be watched, hacked, or otherwise harmed by using technology.

For many, there was a general disinterest in being on the phone or in front of a computer for any great length of time, even just one hour per day to allow the provider to bill for the remote service. *People initially excited about using remote services are now reporting “Zoom fatigue” and their participation has decreased.*



Fundraising losses and donor fatigue. In addition to losses of Maryland DDA funding, chapters of The Arc all experienced other revenue losses, especially essential fundraising income.

When the Governor’s executive order closed businesses and golf courses, and banned large gatherings, organizations were forced to cancel spring fundraising events. Many had planned galas, charity golf tournaments and other events designed to raise funds for the services needed but not covered by state funding.

Individual donor fatigue has also been a factor for organizations. Donations are down due to competing needs from other non-profit organizations, as every organization is desperate for funds to provide food, housing, and other basic human needs during the pandemic.

BIG PICTURE—Are people with I/DD able to access needed supports and services?

The average attendance rate each month across all day service options and all chapters of The Arc was 84% prior to March 2020. *Since the pandemic in Maryland and the Governor’s Executive Orders, the average attendance rate for April and May across all day service options and chapters of The Arc dropped to 43%.* This calculation includes individuals who utilized remote or telehealth supports during this period.

50%↓ **The data shows a decline in service utilization of nearly 50%.** The decline has meant organizations are unable to provide and receive funding for essential services. The loss of ability to secure revenue leaves organizations without funds to cover fixed costs they continue to bear, and leaves many people with I/DD and their families without services and supports they need to live, learn, and work in their communities.



Provider losses total more than \$3.8 million. With an inability to support people at full capacity, continuing costs to maintain the business to satisfy service provision needs and state documentation requirements, the effort to maintain the critical DSP workforce, and tens of thousands in non-reimbursable health-related expenses, losses across The Arc network alone totaled more than \$3.8 million dollars (\$1.785 million dollars in April and an additional \$2.079 million dollars in May). *These losses are like nothing ever before seen in the history of community-based services.*

Most of The Arc organizations have maintained their workforce, somewhat due to relief provided by federal PPP loans, but they report considering future furloughs of workforce or layoffs if conditions don’t improve. *One organization reported that although they maintained the employment of 100% of their workforce, they still received 70 claims for unemployment benefits which include the Families First Coronavirus Response Act additional benefit amount of \$600 per week.*



Program admissions are halted and likely to decline. Another organization noted that they had been aggressive with admissions previously to expand services to those in need. This has come to a halt with the pandemic. The organization reported having over 50 people with disabilities “in the pipeline” prior to COVID-19, with about 20 people (not including Transitioning Youth) who were in the process of securing services.

These admissions are now on hold due to financial uncertainty and the pandemic. *The ripple of this will not only affect the individuals with I/DD, but also their families and the state's economy if parents continue to be unable to work due to a lack of support services and the responsibility to care for their adult children at home during the day.*

LESSONS LEARNED



The future must look different. While many things will eventually return to pre-pandemic states, there are many things that are permanently altered. The movement for I/DD services and supports to be completely in and of the community is critical and a positive development away from large group homes and sheltered workshops. *Medicaid HCBS waiver rules supporting this push are embraced by the I/DD community and must be implemented.*

DDA services are still dictated by “group funding” formulas and matrix levels. Historically, funding has been allocated to daytime services in groups of 4-8 individuals who are in close proximity with each other. Typical staffing for these group has been 1-2 DSPs, tasked with assisting individuals as they participate in community activities, educational and recreational experiences, group work or group volunteerism. Transportation services varied but were usually provided for groups of 5-11 people, who were picked up at their homes in the morning and transported to a common location to start and end each day.

With CDC recommendations to limit group sizes, expand distances of proximity, expand cleaning protocols, and place additional consideration and care on the needs of people with underlying health conditions and advanced age, everything must be re-examined.

The DDA system will need to redesign services, considering one person at a time, with particular attention to their interests and need for health and safety. Groups will need to be smaller. Transportation will need to be less congregate. People with underlying health conditions and advanced age may be advised to stay home for several more months, or until there is a vaccine for COVID-19, and they will need support in that setting.

In addition, consideration must be given to people with disabilities who cannot tolerate wearing a mask. They may experience extreme discomfort and feelings of asphyxiation due to a heightened sensory condition, or may be unable to wear a mask because their airway cannot be obstructed, even by a sheet of fabric.



State leadership, including DDA, must support reconsideration of each person's needs, recalculation of how support will be provided, and ensure adequate funding. It will take time to evaluate the needs of each person and family supported by DDA as a result of new health and safety recommendations, but it must be done.

People with I/DD, once funded for support in groups, will need additional funding to move to 1:1 or smaller group support. This will require an expansion of the workforce, which brings its own

challenges. Prior to the pandemic, it was well-documented that DDA funding was insufficient to compensate DSPs at little more than minimum wage.

DSP turnover across provider organizations is between 40 and 50% per year with almost half of all DSPs exiting within the first 6 months of employment. The hours are long, and the work intense. The position requires skill, patience, organization and compassion.

Essential DSPs have been on the front lines of this pandemic since its beginning. They put themselves at risk every day as they work to support fellow Marylanders. Supporting people individually or in smaller groups will require higher autonomy and decision-making ability.



Transportation may never be the same again. Group transportation is always less costly, but we embrace a move away from this model toward more individualized transportation. This is absolutely necessary but requires a commitment to adequate funding.

As recognized by the DDAⁱⁱ, the funding component for transportation was already inadequate prior to the pandemic. *The new rates that were developed (but not included in the Governor's FY21 budget), would have increased the transportation services rate components significantly.*



Cleaning services (time to clean, supplies) and protocols must be upheld as we recover. Providers will continue to need PPE for the foreseeable future. These items are not currently reimbursed by DDA in funded rates.

These necessities carry heavy price tags, but none of the costs of services or supplies may be passed on to the people with I/DD who are supported due to Medicaid rules. *State funding is required for PPE, cleaning supplies, and the time to clean, to protect everyone's health.*

RECOMMENDATIONS FOR RECOVERY

Provider organizations like The Arc are transforming services out of necessity and with lessons learned from the pandemic. Transformations take time and additional funding as providers must maintain legacy service models for some people, while concurrently creating and providing new service models for other people. Providers are evolving their services, focusing on each person.

1 *Services for people with I/DD should be flexible and person-centered, with funding that supports meaningful transition, recovery and stabilization of the provider network.*

We recommend DDA works to ensure that people with I/DD have adequate technology and internet/phone service to access necessary virtual supports, and to provide continued billing flexibility for the provision of remote supports.

We have learned that some people with I/DD may be better served through remote support, but they may lack the resources to purchase essential technology and internet/phone service. If it is financially advantageous to the state and advantageous to the person with developmental disabilities

and their family to pivot supports from in-person supports to remote supports, the state should consider the cost and quality of benefits that may be created by providing the technology (including internet/phone access).

We recommend DDA supports providers as they implement statewide guidelines about social distancing, cleaning and infection control, and decreased group sizes, in addition to providing flexibility about service delivery for highly vulnerable people.

As the state reopens, people will need to continue social distancing, adopt additional cleaning and disinfecting protocols, and decrease group sizes across all programs and services. Providing services in smaller groups will require changes to transportation, spaces, and staffing ratios, plus additional hiring and onboarding of staff, and associated increases in overhead operating expenses.

People with I/DD who are older or have other pre-existing conditions which would make them highly vulnerable to serious effects of COVID-19, or who have an intolerance to wearing masks, will likely need to be phased back into their support services later, with associated increased costs. There must be a mechanism for accessing funding support to address these situations fairly and effectively.

In addition, billable services and supports should allow reimbursement for additional cleaning supplies and time to clean, and for additional costs of smaller transportation arrangements. This is necessary to keep people safe and healthy now and into the foreseeable future.

We recommend the state commit resources to reduce the impact on I/DD service providers who have experienced hardship during the COVID-19 pandemic.

In the past, DDA providers may have been able to rely on their organization's financial reserves or fundraising efforts to bridge the impact of system changes, but reserves have disappeared during this crisis. *According to a recent survey by ANCORⁱⁱⁱ, most disability support organizations have on average only 1.2 months of funding left for reserves at this time,* clearly placing them in an unstable position and incapable of self-funding any meaningful transformation of service models.

The state budget for Developmental Disabilities Administration Services in FY2020 was approximately \$1.3 billion, half state funded and half federally funded. To aid the recovery of provider organizations and to fill some gaps created by an inability to bill for services during the pandemic, the state should allow for the payment of at least the "state-only" portion of the funding in the budget, regardless of program attendance. While this will not entirely cover losses, it would help to restore stability to hard-hit provider organizations and aid in their ability to re-open.

Maryland has designated HCBS providers as essential health care workers, but DDA funding has not been enhanced to provide incentive and hazard pay for working in potentially dangerous environments. Hazard pay is only reimbursed by DDA at a rate of time plus one-half for DSPs working directly with someone who is presumed or confirmed positive for COVID-19.

This starkly contrasts to enhanced pay provided to other essential workers in Maryland, many of whom the state has funded. Those workers *do not* have a requirement that they be working directly with a person who is positive for COVID-19 before the enhanced pay is provided.

We also ask our state leadership to prioritize PPE for DSPs who work in small congregate settings, and often with individuals who may have an inability to exercise handwashing, cough-covering, and social distancing, placing everyone at advanced risk of illness.

We recommend the state increase ongoing funding for developmental disability providers so they may transform and continue to deliver essential services and supports.

DSPs are the backbone of our extensive system of developmental disabilities services and supports. It is time to recognize them with pay that is commensurate with their levels of responsibility, training, competencies, risks, and autonomy.

This valuable caregiving workforce is at risk of collapse. For many years, DDA funding was increased only modestly and has not kept pace with increases in costs of living and doing business. As the state minimum wage has increased over the past several years, the delta (between minimum wage and the starting wage of DSPs) has become flat and in one county, inverted. DSPs have been lured away from the field by the promise of better conditions to work in retail and fast food—jobs with less stress and responsibility for the same or greater pay and benefits.

Rebuilding this essential workforce will only be possible with increases to DDA funding to support pay increases and pay-related expenses for DSPs.

2 *A portion of the federal emergency relief funding provided to Maryland should be designed for developmental disabilities services recovery.*

We recommend the state allocate funding specifically for DDA providers as part of the FFCRA.

As part of the Families First Coronavirus Response Act (FFCRA) Maryland is receiving a 6.2% increase to our federally-matched Medicaid funds. Eligibility for the increase is effective January 1, 2020 and extends through the last day of the calendar quarter in which the public health emergency, declared by the Secretary of Health and Human Services for COVID-19, terminates.

The majority of this funding is likely allocated to hospitals and coronavirus healthcare efforts such as testing and treatment and including expansions of Medicaid insurance coverage. However, DDA providers deliver Medicaid services upon which a portion of these additional federal matching funds are being drawn and brought into the state revenues and should receive additional funding support.

We recommend the state allocate funding specifically for DDA providers as part of the first disbursement of the CARES Act.

In addition, Maryland is receiving relief funding through the Coronavirus Aid, Relief, and Economic Security (CARES) Act. According to KFF, Maryland has received at least \$742,225,306 in the first disbursement of the CARES Act Payments.^{iv} Division B of the CARES Act provided \$100 billion nationally to reimburse hospitals and other health care entities responding to coronavirus for health care-related expenses or lost revenues that are attributable to coronavirus.^v

In our neighboring state of Pennsylvania, the Senate recently took action to approve the allocation of \$260 million of their federal CARES funding for providers of intellectual disability and autism services for critical needs created by the COVID pandemic.^{vi} If Maryland has received CARES Act funding

under Division B, we ask that a portion be devoted to relief for our DDA providers as an eligible “health care entity,” in reimbursement for expenses incurred responding to the coronavirus, health care-related expenses, and lost revenues attributed to coronavirus.

CONCLUSION

DDA is currently working with the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and other state directors on the framework for a reopening plan. They also plan to survey providers on their capacity to reopen and gather information from families about what has worked for them during this time, what has not worked, what they need and what they want for the future.

We are hopeful that DDA will widely solicit and incorporate feedback from providers, family members, and people with I/DD to develop the guidance on appropriate reopening practices for settings serving people with disabilities.

We encourage collaborative and transparent discussions with all stakeholders to discuss the impacts of the pandemic to the health of people with developmental disabilities, provider organizations, and families, exploring and sharing lessons learned and determining how we emerge from this pandemic vital, efficient and effective. The discussions should collaboratively explore what resources we may need initially and ongoing to ensure people with disabilities and their families in Maryland are fairly and effectively supported. *Only then will we have the ability move forward in health together.*

The Arc chapters collectively offer our ideas and commit our administrative time and support to this shared purpose—the development of our post-crisis framework for developmental disabilities services and supports in Maryland.

Respectfully Submitted,

The Arc Baltimore
The Arc Carroll County
The Arc Central Chesapeake Region
The Arc of Frederick County
The Arc Howard County
The Arc Maryland

The Arc Montgomery County
The Arc Northern Chesapeake Region
The Arc Prince George’s County
The Arc Southern Maryland
The Arc Washington County

ⁱ <https://governor.maryland.gov/wp-content/uploads/2020/03/Gatherings-THIRD-AMENDED-3.23.20.pdf>

ⁱⁱ https://dda.health.maryland.gov/Pages/Responses_to_Rate_Study_Questions.aspx

ⁱⁱⁱ https://www.ancor.org/sites/default/files/impact_of_covid-19_on_organizations_serving_individuals_with_idd.pdf

^{iv} KFF Analysis: Number of Coronavirus Cases, Distribution of \$30B in CARES Act funding and Medicare Advantage Penetration by State (kff.org)

^v KFF: The Coronavirus Aid, Relief, and Economic Security Act: Summary of Key Health Provisions (kff.org)

^{vi} <https://www.pasenategop.com/blog/senate-republican-leadership-passage-of-budget-cares-funding-sets-course-for-recovery/>