CLOSING THE GAP BETWEEN FUTURE NEEDS AND RESOURCES FOR PEOPLE WITH INTELLECTUAL DISABILITIES

A JOINT STUDY BY THE UNITED WAY OF ALLEGHENY COUNTY AND CARNEGIE MELLON UNIVERSITY’S H. JOHN HEINZ III COLLEGE
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PART I: EXECUTIVE SUMMARY

Almost everyone will need a caregiver at some point in their life. We have caregivers when we are children and we will likely rely on a caregiver when we grow old. While most of us will only need caregivers for certain periods in our lives, others will require constant attention. Caregivers of individuals with intellectual disabilities often find themselves in the latter situation. Facing significant responsibilities, they frequently need additional assistance from the state and non-profits. By considering how to better serve the caregivers of individuals with disabilities, the state will be assisting individuals who play a vital role in our society. Additionally, since many other people will rely on caregivers at some point in their lives, improved services to caregivers of individuals with intellectual disabilities will translate to an enhanced system of care for all.

In looking at the needs of caregivers of adults with intellectual disabilities, three issues arise that, when combined, indicate a need for additional support for this population in Pennsylvania. These issues are:

- Pennsylvania has more caregivers who are 60 years of age and older.
- Allegheny County is experiencing an aging population.
- The cost of long-term care has continued to rise.

As the general population ages, segments of the population will follow this trend, including the large population of caregivers in Pennsylvania. As we age, complications arise in our general health and end of life issues become challenges we must face in our everyday lives. These issues become elevated for individuals with intellectual disabilities, as well as those tasked with caring for them. This situation is further compounded given that caregivers in Pennsylvania are already older than caregivers in the rest of the US. Thus, the system in Pennsylvania faces greater strain when compared to other states.

In order to quantify this growing need for services, projections of waiver enrollment and service costs were completed. In the status quo and enrollment analysis, it was found that enrollment would increase. In addition, it was found that per person costs are increasing, which puts pressure on a state budget already squeezed by financial and political factors. As a result, people who require services may be pushed out of the system.

Therefore, recommendations were formulated to improve the system as it currently stands. These recommendations were developed by determining best practices in other states’ systems. The states were selected on several criteria, including fiduciary efficiency and consumer satisfaction. The evidence was then applied to the work that Pennsylvania is currently doing.

Summary of Key Findings:

- **Per person costs will continue to rise in Pennsylvania.**
  
Pronjections based on historical cost data at the state and county level over the last five years shows future costs will continue to rise.

- **If funding stays the same, people could be crowded out of the system.**
  
If funding stays constant and per person costs continue to rise, people who previously received services could be pushed out of their programs. Pennsylvania will need to consider the implications of leaving people without needed long-term care assistance.

- **Data collection should be more comprehensive.**
  
Currently the data collected on caregivers receiving state Medicaid services is limited. Information
on caregivers as well as quality assurance assessments will better enable Pennsylvania to serve this population.

- **Strategic Planning needs to be more robust and include as many voices as possible.** Strategic planning is fragmented among many committees. These various teams should align their objectives to work towards shared systemic goals.

- **All agencies under the Department of Human Services should develop specific measurable goals.** Measurable goals should be made on an annual basis at both the state and county level for each agency - ensuring that progress can be tracked and providing clear targets to work towards.

- **Pennsylvania’s progress toward a better system of care should be made easily accessible.** Directly related to the notion of measurable goals is the priority to report the progress toward those quantitative objectives. Providing the public with a forum that allows them to keep these committees accountable toward their goals will bolster their efforts and ensure success.

- **Pennsylvania should focus on supporting caregivers.** Caregivers represent a significant contribution to the care of adults with intellectual disabilities. The state should consider the extra resources it would require to replace those caregivers and have that amount inform the depth of services they provide to them. Seeing caregivers in this context will illuminate the critical role they play; the state’s policies should reflect that reality.

- **Care should be integrated across long-term service providers.** Many states have moved to an integrated model so that people who require long-term care are treated consistently. This means long-term services are similar across the organizations that provide them. In doing the same, Pennsylvania would improve the supports provided.

- **Pathways to information need to become more consistent and informative.** People seeking long-term services search for information through a variety of different channels and start from a variety of different organizations. The state needs to ensure that no matter where people start they end up with the same information, they find the agencies they need, and they are connected to the services needed in their particular situation.

- **Assistance should be provided to people considering alternative methods of care.** Unique models of care, such as Microboards, have been recently developed to support families caring for adults with intellectual disabilities. Forming a Microboard requires a great deal of skill and perseverance, but removes a lot of onus from the caregiver as the individual with intellectual disabilities ages. Since programs like Microboards can be very beneficial to caregivers, the state should help support this method of care.

- **Pennsylvania should focus on an inclusive model of care.** Oftentimes the goals and desires of the person receiving services are filtered through their caregiver or the agencies serving them. Furthermore, people with intellectual disabilities are often kept separate from society at large. Pennsylvania should create structures where people with intellectual disabilities can represent themselves and advocate for their own desires.

Overall, Pennsylvania is at a liminal stage in the evolution of supports for caregivers of adults with intellectual disabilities and adults with intellectual disabilities themselves. Capitalizing on the momentum behind this important work will be critical to changing the system that serves this population.
PART II: INTRODUCTION

In December 2013, Port Vue resident Richard Liposchok took the life of his 52 year old son with intellectual disabilities as well as his own. This tragedy brought to light the horrible choice that older caregivers of adults with intellectual disabilities feel they face as both they and their child grow older. This population is currently underserved in Allegheny County; as of 2014, there are 1,273 people on waiting lists for services.1 If the population of those with intellectual disabilities continues to grow while funding for services does not change, what will the future look like for those with intellectual disabilities?

PRIOR WORK

Since that tragedy the United Way of Allegheny County has taken a variety of steps to mobilize change around this issue.

In early spring of 2014, meetings were conducted with a host of local community leaders in order to learn how the system works for those trying to access services Allegheny County. These meetings provided insight into the system, uncovered drawbacks, and proposed changes that could make an impact in the lives of those with an intellectual disability. Many of these community leaders were also invited to participate on the Advisory Committee of the Heinz project and provided invaluable direction.

Additionally, the United Way conducted initial research in summer of 2014 for background to the current study. Included in this research was: the historical context of the Disabilities Rights Movement, the overall system of delivery for those who have an intellectual disability, the past and the current legislation that make a difference in the lives of someone with an intellectual disability, and the work that United Way has done for those who are about to age out of the system at 21 years old.

SCOPE OF THE PROJECT

The primary purpose of this report is to provide evidence from which stakeholders involved in this type of work can create positive change. This study:

• Offers projections on the future associated costs of service.
• Provides recommendations to better address the needs of this population given the current service options and planning processes taking place.
• Addresses wider issues regarding individuals trying to access long-term care services in Pennsylvania.
CURRENT FUNDING STRUCTURE

Currently the intellectual disability system is set up in the following way:

- Federal funds come from the Centers for Medicare and Medicaid Services (CMS). CMS provides funding for supports for people with disabilities.
- Pennsylvania Department of Public Welfare (DPW) and Pennsylvania Office of Developmental Programs (ODP) allocate funding through legislative budgeting process. The amount of appropriated state funding is matched by the federal government through CMS.
- County programs enroll individuals into the Waiver program and authorize services outlined in Individual Support Plans (ISPs).
- ISPs are developed to outline services needed. An individual chooses who will provide the services and a budget is created. Once the County authorizes the plan, the providers of waiver services bill the State Treasury for payment of provided services.

KEY TERMS

- Waiting List – The Waiting List is comprised of individuals who are qualified and eligible to receive services and supports throughout the Office of Developmental Programs waivers, however, due to insufficient resources, the state cannot currently meet their needs.
- Waiver – Waiver is a shortened term for Medicaid Home and Community-Based Services Waiver Programs. Waivers provide the majority of the funding for the Pennsylvania Intellectual Disabilities supports and services.
- Home and Community-Based Services (HCBS) Waivers – Waivers generally support people in their own homes, in their family home, in a family living home, or in group living arrangements
- Consolidated Waiver – one of the HCBS waivers. Under this waiver, the plan must be appropriate to meet the person’s needs and there is no individual cap.
- Person/Family Directed Support (P/FDS) Waiver – another HCBS waiver. Under this waiver, amount for services provided is capped at $30,000 annually.
- Supports Coordinators – Assigned by the County Intellectual Disability system. They are responsible for making sure all steps leading to applying for and receiving Intellectual Disability Services are followed.

PERSON CENTERED PLANNING

Person centered planning is an important concept that informed our recommendations. Person centered planning is a planning process that believes each individual should be at the center of planning for their own life. This is not to say that others should not have input, as the input of others into realistic goals is incredibly important and valued in this concept, but that the person whose life it is should have the ultimate decision making capabilities when discussing their own life. This is especially seen in the creation of their individual service plan, as it should focus on their current needs and future goals and change and grow with the person.

Person centered planning also benefits from learning from shared experiences. By sharing what is learned with each individual going through the planning process, person centered planning can serve as a repository of best practices for others who are about to undertake the planning process for their own lives. Person centered planning also allows a forum through which one can address the conflicts that inevitably come up when planning for the future.
For many years, those with intellectual disabilities were not given a say in their own lives because it was believed that they did not have the intellectual capability to do so. However, with greater understanding and compassion, it has been proven that this opinion is entirely false and that those with intellectual disabilities have a right to direct their own lives. This shift has been taking place over the last several decades throughout the United States as well as on the federal level. This project is an extension of those changing beliefs; person centered planning is essential to the recommendations this project produced for Allegheny County and Pennsylvania.
PART III: FRAMING THE PROJECT

The need for services targeted towards caregivers of individuals with intellectual disabilities is quite great. This need can be described through two main points: First, Pennsylvania has more caregivers who are 60 years of age and older. Second, Allegheny County is experiencing an aging population, meaning the average age of Allegheny County is increasing each year. Our hypothesis is that the proportion of elderly caregivers in Pennsylvania and Allegheny County will continue to grow due to the aging population and the higher propensity of elderly individuals as caregivers. As people age, their own self-care becomes more complicated, let alone the care of an adult with intellectual disabilities. This translates to an even greater need for services targeted towards aging caregivers. The following graphs depict these demographic changes and further show the growth of the population in need.

A LARGER PROPORTION OF CAREGIVERS 60+

Figure 1 shows that Pennsylvania has a larger proportion of caregivers aged 60+, as compared with the U.S. overall. Twenty-nine percent of caregivers in Pennsylvania are aged 60+, compared to just 17% of caregivers in the United States. Another way to say this is that Pennsylvania’s population of caregivers aged 60+ is 12% higher than the rest of the United States.

Figure 1. Percentage of Individuals with I/DD and Caregiver 60+ vii

![Bar graph showing percentage of individuals with I/DD and caregivers aged 60+ in Pennsylvania compared to the United States.]

Looking at just the state of Pennsylvania, we see in Figure 2 that caregivers aged 60+ make up almost a third of all caregivers. Caregivers under the age of 41 and caregivers aged 41-59 make up 36% and 35% of all caregivers, respectively.

Figure 2. Ages of Caregivers in Pennsylvaniaviii

As mentioned earlier, as people age they face additional considerations in taking care of themselves. Combining their own difficulties with the task of caring for a disabled child can put significant burdens on the caregiver. The high proportion of caregivers aged 60+ demonstrates there is a sizable target population for improved services.
ELDERLY POPULATION IS PROPORTIONALLY LARGER

The proportion of adults aged 65+ in Allegheny County is projected to increase for the next 15 years. In Figure 3, we see that proportion is expected to increase from 17.7% in 2015 to 21.9% by 2030. This proportion will be higher than the proportion in the US until 2040, when the rest of the US is expected to catch up.

Figure 3. Proportion of Allegheny County and US Population Aged 65+

Figure 4 shows us the same information, but in terms of percent change. By 2025, the population aged 65+ in Allegheny County will be increasing at a rate of 2% per year until the foreseeable future. While significant, the effect is reduced by 2035 when growth of the proportion aged 65+ will stagnate, as seen in Figure 3. The cause of this is that by 2035 other age groups will be increasing at a faster rate, meaning the proportion aged 65+ will not be increasing.

Figure 4. Growth of Population Aged 65+ in Allegheny County
We can examine the effect aging has had on caregiver ages by turning to HCBS waitlist data in Allegheny County. Figure 5 shows the percent of waitlist enrollees with caregivers aged 60+. Fiscal year 09/10 saw 10% of waitlist enrollees with caregivers aged 60+; by 14/15 that percentage had spiked to 21%. Combined with an overall aging population, it is not unreasonable to expect these percentages to continue increasing.

**Figure 5. Individuals on HCBS Waitlists in Allegheny County with Caregivers Aged 60+**

![Graph showing increase in percent of waitlist enrollees with caregivers aged 60+] xi

**CONCLUSION**

Pennsylvania has relatively more aging caregivers than the rest of the United States. Also, Allegheny County is experiencing an aging population.

Turning back to some of our earlier data, we can extrapolate how the aging population will effect the age distribution of caregivers. In Figure 2, we saw 35% of caregivers in Pennsylvania are aged 41-59. Due to the aging process, many of those individuals aged 41-59 will continue to be caregivers when they are 60+ (barring any significant changes in caregiver status). This means that in the near future Pennsylvania could very well expect to see close to 35% of caregivers aged 60+.

This information has two main implications. First, Pennsylvania and Allegheny must be prepared to meet the additional requirements that a larger elderly population will present. Second, having more elderly caregivers will cause Pennsylvania to have a greater strain on their system. In as little as 15 years the services demanded from the system by the increased population of elderly caregivers could vastly increase.
PART IV: COST & ENROLLMENT PROJECTIONS

To understand the extent to which current policies will be able to serve the target population, enrollment and per person spending projections for the Consolidated and P/FDS waivers in Allegheny County and Pennsylvania were conducted. The projections show that enrollment and per person spending will continue to increase for both waivers. This section will begin by discussing the data utilized and then move on to a description of the projection methodology. It will conclude with a presentation and discussion of the projection results.

DATA

Data for our analysis came from Allegheny County Department of Human Services and the Pennsylvania Office of Developmental Programs. The county data includes individual enrollment data for fiscal years 2007-2008 through fiscal year 2013-2014. This enrollment data provided the number of individuals enrolled for the seven years, plus their age, race, disability severity, and the total amount spent on providing their waiver. In addition, the county provided aggregate level enrollment and utilization data for fiscal years 2007-2008 through years 2013-2014.

The State of Pennsylvania provided aggregate level enrollment data for the P/FDS waiver and the Consolidated waiver for fiscal years 2002-2003 through fiscal years 2013-2014. The state also provided aggregate utilization data for fiscal years 2009-2010 through 2013-2014.

METHODS

Appropriate models were built based on the characteristics of the data. The state data contained information on spending for waiver components while the county data contained demographic information. As a result, the state model uses variables for spending changes for waiver components but does not use demographic data. The county model uses demographic data but does not use changes in spending for waiver components. The underlying methodology for all the projections is Monte Carlo simulation, while the county projections also include a marginal analysis component. Unless otherwise noted, the models followed the same procedures for both the Consolidated and P/FDS waivers.

State Projections

Total spending for 18 waiver components under the Consolidated Waiver and 14 waiver components under the P/FDS were given to us for years 2007-2014. Not all of the waiver components would go on to be utilized in the model as some of the components represented a very small percentage of the total yearly spending. The percent change in each of the waiver components was calculated from years 2007-2014. Next, the percentage of the total yearly spending the components represented was calculated for 2007-2014. Random variables (RVs) were created for the percent of total spending and percent change metrics for each of the waiver components. A weighted average was calculated by multiplying the percent of total spending RV and percent change RV for each waiver component, then summing all of the resulting values for years 2007-2014. A “final RV” was created from the resulting calculations.

The simulation was started by increasing the 2014 cost by the final RV. This was then simulated 1,000 times to allow the RV to change with each simulation. The average of these values was used as the 2015 total cost. To get per person costs, the total cost was divided by the simulated enrollment (discussed below). This process was then repeated for the remaining projection years.

County Projections

The model for per person spending on the county level utilized a more complex model that took into account demographic data. To build this model, a two-step process was used. First, a regression model was built for the P/FDS and Consolidated waivers to examine how age affected costs. The regression
model used total spending for person i in year j as the dependent variable and age as the independent variable, while controlling for race, sex, severity of disability, and the year. The full model is below:

Log Total Spending = Age + Age^2 + Black + Asian + Hispanic + Male + Moderate + Profound + Severe + Year

Log Total Spending is the log of the amount spent on individual i in year j. Age is the age of person i in year j. Age^2 is to account for variability in spending. Black, Hispanic, and Asian are dummy variables for race. Male is the dummy variable for gender. Moderate, Profound, and Severe are dummy variables for the disability classification of an individual. Year indicates what year it is. After the regression was done, a margins analysis was performed to obtain the coefficient for age. The tables below contain the coefficients and p-values obtained.

### Table 1: Consolidated Margin Analysis Results

| Variable | Coefficient | Standard Error | P>|t| |
|----------|-------------|----------------|---|
| Age      | 0.0020031   | 0.0004116      | 0 |
| Male     | 0.0593258   | 0.0127323      | 0 |
| Black    | 0.0045088   | 0.0161573      | 0.78 |
| Asian    | -0.1721194  | 0.0826055      | 0.037 |
| Hispanic | 0.1475367   | 0.0770367      | 0.055 |
| Moderate | 0.0807718   | 0.0157252      | 0 |
| Profound | 0.2311374   | 0.0183045      | 0 |
| Severe   | 0.1327507   | 0.0178724      | 0 |
| 2012-2013| -0.0120833  | 0.0228281      | 0.597 |
| 2011-2012| -0.0210875  | 0.0229003      | 0.357 |
| 2010-2011| -0.0471744  | 0.0229289      | 0.04 |
| 2009-2010| 0.015002    | 0.02296        | 0.514 |
| 2008-2009| -0.2024271  | 0.0232019      | 0 |
| 2007-2008| -1.240127   | 0.0236778      | 0 |

### Table 2: P/FDS Margin Analysis Results

| Variable | Coefficient | Standard Error | P>|t| |
|----------|-------------|----------------|---|
| Age      | 0.0103305   | 0.0009031      | 0 |
| Male     | 0.0278402   | 0.0214449      | 0.194 |
| Black    | -0.0126338  | 0.0264234      | 0.633 |
| Asian    | 0.1992929   | 0.1383771      | 0.15 |
| Hispanic | -0.1430418  | 0.1355974      | 0.292 |
| Moderate | 0.2766266   | 0.0228501      | 0 |
| Severe   | 0.3923368   | 0.0392321      | 0 |
| Profound | 0.4228236   | 0.0773508      | 0 |
| 2012-2013| -0.04181    | 0.0377732      | 0.268 |
The second part of the model utilized the Monte Carlo method described in the state projections. Two random variables were created. One was the percent change in per person costs for years 2007-2014. The second was built from the confidence interval of the age coefficient from the margins analysis. To begin the simulation, the 2014 per person cost was increased by the percent change RV and the Age coefficient RV. This value was then simulated 1,000 times. The average of these 1,000 values was used as the 2015 per person costs. This process was repeated for each subsequent projection year.

Enrollment
For both waivers at both geographies, the percent change in enrollment was calculated for years 2007-2014. A RV was then constructed from this distribution. The simulated was started by increasing the 2014 enrollment by the enrollment random variable. This value was then simulated 1,000 times. The average of these values was used as the 2015 enrollment. This process was then repeated for the remaining projection years.

At both the state and county levels, the maximum value the enrollment RV could take on was a 20% yearly increase. From an analysis of the current political and fiscal climate in Pennsylvania, as well as past trends, this seemed unrealistic. Governor-Elect Tom Wolf has made it a priority to increase education funding, but the Republican controlled legislature is not expected to raise taxes. For both groups to have their way, spending in other areas will have to be cut. The state also faces a $1.85 billion budget shortfall that will create additional pressure to cut spending. Finally, the average yearly increase in enrollment for the P/FDS waiver has been 3% per year (excluding one outlier year). This led us to cap the maximum allowable yearly enrollment increase at 4% per year.

RESULTS
The results below are split into two parts. First, enrollment projections for the P/FDS and Consolidated waivers are discussed. Second, the per person spending results are discussed, including notable limitations of the results.

Enrollment Projections
In Figure 6, we see there is a notable difference in enrollment increases between the Consolidated and P/FDS waivers. The enrollment for the Consolidated waiver is projected to increase by 7.6% over the next five years while the P/FDS waiver is expected to increase by noticeably larger amount of 13.7%. This difference likely reflects the fact that the Consolidated waiver is more expensive than the P/FDS waiver, slowing its enrollment growth.
Figure 6: Enrollment Projections for the Consolidated and P/FDS waivers in Allegheny County

Figure 7 shows the enrollment projections for the Consolidated and P/FDS waivers for the state of Pennsylvania. The Consolidated waiver is projected to increase by 10.3% over the next five years while the P/FDS waiver is expected to increase by 10.1%. The state can reasonably expect steady enrollment increases despite cost and political pressures in the coming years. It is odd that enrollment increases are similar despite the difference in per person costs between the two programs. Future work should test the validity of the enrollment increase and dive deeper to see why a similar enrollment increase would occur.

Figure 7: Enrollment Projections for the Consolidated and P/FDS Waiver in Pennsylvania
Per Person Spending
The second part of our projections involved projecting per person costs. Figure 8 presents per person spending projections for the Consolidated waiver. Both simulations found, despite different methodologies, that per person spending increases 9% for the five-year period. The consistency is surprising and reinforces that spending for the Consolidated waiver will be increasing in the coming years. Although the total increase is under 10% for the five-year period, the Consolidated waiver’s per person costs are already six figures. Consequently, a 9% cost increase may very well represent a significant fiscal burden for the state, leading to a slowdown in the growth of enrollment.

Figure 8: Per Person Spending for the Consolidated Waiver 2014-2019

Figure 9 shows projected per person spending for the P/FDS and Consolidated waivers. As expected, the different methodologies of the projections produce different results. Per person spending for the state P/FDS waiver is projected to increase by 26% over the five-year period. The per person spending for the county waiver shows a steeper increase of 43%. Despite the different methodologies, both scenarios show large increases in per person spending for the P/FDS waiver. This is concerning because the increases in per person costs make it more expensive to care for the existing population and also complicate the state’s ability to cover additional individuals. The increases in per person cost also put more pressure on the state’s budget, since there are less dollars to put toward other programs and initiatives. Consequently, governments may become more restrictive of enrollment to help slow down cost growth. Given the projected budget deficit for the state of Pennsylvania, this circumstance could occur in Pennsylvania, preventing people from accessing beneficial services.
Additional Notes
The effect of the Age coefficient RV was so small that it did not have a major effect on costs. Additionally, the effect of age should also not be taken as the casual impact of age. The reason is the regression did not control for unobservable factors that could lead to a major change in results. For example, enrollees must wait for a period of time on the waiting list before gaining services. The patience of those individuals points to a greater motivation to receive services, which indicates that these people have a larger need than other individuals with intellectual disabilities. If non-enrollees were included who had less motivation, the results could be different.

SUMMARY
Both the P/FDS and Consolidated waivers on the state and county levels can expect to have increased enrollment over the next five years. These values range from a low of 7.6% to a high of 13.7% increase over the next five years. Thus, these programs can expect to serve more individuals with intellectual disabilities. However, the rise in per person costs threaten to curb enrollment growth in the future. The main reason for this concern is the expected political struggle to raise education funding but not increase taxes and close a large state budget gap. This conflict will place large pressure on other line items of the budget to curb costs. The 26% projected increase in the state and the 43% increase in Allegheny County for the P/FDS waiver over the next five years stands out as especially concerning as such a rapid increase in costs could lead to the state curbing enrollment in an effort to minimize costs. Even the more modest increases of 9% in the state and county Consolidated waiver will put pressure to curb costs as per person spending is in the six figures for that program. Overall, this leaves a situation where the Consolidated and P/FDS waivers may very well not be enough to serve the needs of all adults with intellectual disabilities.
PART V: DISCUSSION & RECOMMENDATIONS

As a starting point, the group used the Case for Inclusion to aid in identifying states creating new benchmarks in long-term supports and services as well as developmental and intellectual disability policy. By focusing on states ranked highly in providing services for those with intellectual disabilities in the areas of fiduciary efficiency and consumer satisfaction, three states were identified as models for comparison: Washington, Michigan, and Tennessee. Once these states were identified, their systems of care were examined to identify areas that relate to our target population. Through this process, several overarching, nationwide trends were pinpointed: the value of personhood, inclusiveness, long term supports, and independence.

Comparing those findings with what is currently happening in Pennsylvania was difficult. Information on Pennsylvania’s approach was not readily accessible and often quite challenging to find. With a focus on identifying gaps in service provision and program theory, an initial set of recommendations were developed that focus on improvements in the strategic planning process for Pennsylvania. In addition, methods for empowering change at the community level for those with intellectual disabilities were discovered which could improve Pennsylvania’s system of care.

ASSESSING LONG TERM SERVICES IN PENNSYLVANIA

As the state considers the financial possibilities of the future, strategic planning becomes critical to creating a better system of care. Strategic planning will help the state anticipate the changing needs of this population, develop an appropriate framework for service provision, and deliver apt services. In exploring the state’s approach to strategic planning, significant areas for improvement were identified.

Issues Arising from the Current System

At the state level, there are several agencies within the Department of Human Services working on strategic plans for improving service delivery of both long-term care services and services for people with intellectual disabilities. Each of these individual processes should inform one another and should share a strategic vision. Additionally, the policies and directives stemming from these plans should be in line with the state’s long-term care objectives.

Real-time information on the progress of these activities is not directly available on the Department of Human Services webpage and is not easily accessible to the general public. Making an intentional effort to provide this information to stakeholders should be made; doing so would enable more people to be involved, improving the overall outcomes of these efforts. Furthermore, there is minimal way for these committees to be held accountable by the public. It is difficult for their progress to be tracked by the population at large due to the way this process is made public.

It is troubling that the current strategic planning teams in the state of Pennsylvania presently neglect to acknowledge the valuable role that unpaid caregivers play in the system. Any future policy planning that does not recognize the major contributions and needs of this population would be missing a key component of the informal support network that cares for this population.

In discussing these issues it is also prudent to keep in mind the changing needs and growing demands of inter-related target populations. For example, in Pennsylvania there must be a balance between providing a sufficient level of quality group homes to promote independence, as well as provide needed supports for family caregivers of those with intellectual disabilities. The large elderly population and the number of aging caregivers in the state create an immediate need for long term care services focused on supporting those family and friends currently caring for dependent loved ones. At the same time, service providers and advocates are pushing for a system that encourages viable opportunities for adults with intellectual
disabilities that would afford functional community integration and habitation in the broader community. Both of these simultaneous pulls on the current system are motivated by a desire to help individuals with disabilities continue to live integrated in their community, in their own homes, and out of costly institutional care settings.

Yet, historical attitudes around the ability and personhood of those with disabilities, deeply imbedded by decades of policies reinforcing dependency and isolation, make it so shifting societal beliefs and system-level policies will be a slow, stepwise process. Nonetheless, the state must act with urgency. The immediate need is large in scale. The aging parents and caregivers of those with intellectual disabilities cannot afford to wait for a new generation to provide them with the assistance they are in desperate search of right now.

Critiques of the Current Strategic Planning Process

Pennsylvania has initiated this conversation in several system-level work groups tasked with future planning around long term care and disability services. Below are two of the current processes taking place within Pennsylvania that deal with the target population. With the process still ongoing, the state should consider filling the gaps identified below.

I. ODP Futures Planning

The state’s Office of Developmental Programs (ODP) is conducting an agency-level strategic planning process. ODP staff members, stakeholders, and members from other DHS agencies have been divided into several distinct workgroups to draft recommendations and devise strategies for implementation. Futures Planning currently includes eight high-level objectives:

1. Each person’s budget is based upon assessed needs, and the individual will know and be able to control the services within their budget.
2. Review and revise qualifications so that people will be supported by professionals who are appropriately qualified and trained to their individuals’ needs, including a focus on people with complex physical or behavioral health needs.
3. Define a process to support creation of and funding for newer, better, reduced-cost ways to provide services.
4. Integrate flexible models of service that can support peoples’ changing needs in their home communities, including supporting people through a physical or behavioral health crisis.
5. Determine the best and simplest system to manage services to improve outcomes.
6. Develop steps to define quality measures. The results of the measures then can be used to develop an action plan to improve quality of life for those supported by the ODP system. ODP will work with individuals, families, providers and others to develop meaningful measures that go beyond the minimum standards.
7. Develop design options for a pilot program for managed care of developmental disability services.
8. Pennsylvania will be an Employment First state. Employment is the first priority for people with disabilities.

The next steps ODP has laid out for this process include developing action plans for each of the objectives above, soliciting feedback through public comment sessions across the state, and creating plan for implementing these new directives.

II. The Governor’s Commission on Long-Term Care

At the system level, Governor Corbitt’s Commission on Long Term Care is devising the state’s Balancing Incentive Program (BIP) in accordance with the Patient Protection and Affordable Care Act of 2010. According to the state’s application for funding, Pennsylvania currently ranks third in the nation for
Medicaid expenditures on home and community based Long Term Services and Supports (LTSS) and 42\textsuperscript{nd} in the nation for the amount of spending on community-based LTSS versus institutional care.\textsuperscript{xvi} As part of this initiative, from July 2014-September 2015 the Center for Medicaid and Medicare’s (CMS) is providing a 2% increase in the federal match as an incentive to help states that previously spent less than 50% of their long term care funding on home and community-based services restructure and refocus their policies to provide support in less restrictive settings.\textsuperscript{xvii}

There are three required components to this funding opportunity that states must include in their rebalancing changes: (1) a No Wrong Door, single entry-point system; (2) Core Standardized Assessments; and, (3) Conflict Free Case Management.\textsuperscript{xviii}

The first of these eligibility requirements, the No Wrong Door model, is designed to make it easier for people to learn about and access LTSS across all of the various agencies and departments. Right now making decisions about long term care in most states is a complicated process involving many different funding sources and barriers to entry. The individual trying to access services must gather information, screen for eligibility, and develop a care plan based on options from several disjointed agencies. The BIP calls for a more streamlined process to be put in place to screen and enroll people trying to access services across the state’s various programs and agencies. The intent is that all people regardless of their age, disability, income level, and even payer mix could connect with the whole system of LTSS by going to a single place that would provide options, counseling and eligibility screening for individuals. These central hubs would help people make these important decisions based on system-level guidance and complete information to reduce individuals’ stress and burden and to avoid people making suboptimal, costly decisions about their care or the care of a loved one.

Along with central hubs, 1-800 numbers and 211 hotlines across the state should be included as partners in this effort, offering information to participants and directing them to visit the appropriate centers in their area. Also, all online communication platforms serving the target population should direct users to a single informative website, accessible to a diverse audience of users of varying functional ability. The current online infrastructure offers fragmented information across a host of agencies web pages. Instead a web-based screening tool should be created to lead the user through a series of questions to determine their circumstantial needs as well as the programs for which they qualify.

Case coordinators currently work with a knowledge of the programs housed under their respective agency. In line with the Commission’s push for interconnectivity, staff members should receive training across agencies in order to understand the nuances of where individual clients and their service needs would fit into Pennsylvania’s overall system of long term care.

When an individual comes into or calls an office to discuss the different programs offered under the Department of Human Services, any staff member should be able to answer their questions. Providing better assistance would require staff to attend a training that discusses the program available to individuals with a disability, to individuals who are aging, or individuals who are a caregiver, plus any other individual’s that are covered by the DHS. This ensures that everyone understands where people can turn to when in need of assistance specific to their requirements.

Each year the Allegheny County Area Agency on Aging (AAA) provides a conference for the case managers. One session at that conference includes a case coordinator from the Office of Intellectual Disabilities that explains how to work with that specific population and the challenges they exhibit. This type of session could be done for the case coordinators by the case managers of AAA. An annual session would provide a formal setting to create new informal networks so that all case coordinators are better equipped to help the individuals they interact with daily.

The second requirement under the BIP funding initiative is to develop “conflict-free case management services”. This means putting in place processes and oversight policies to ensure that case managers who help conduct these core standardized assessments and determine eligibility for services are done
separately from direct service provision. The goal of this is to make sure consumers' eligibility is not compromised by those making the determinations for their own financial gain or to increase business of the provider. Along with these measures should come strong oversight and clear, accessible channels for receiving and tracking consumer appeals and grievances about the quality and outcomes of their care.

Under the funding requirements, the final component of this change process is to create and implement a uniformed, “core standardized assessment”. This assessment it to be used to determine an individual’s eligibility for Medicaid funded, non-institutional LTSS, to identify their unique needs related to long term care, and to develop an individualized, person-centered care plan based on those factors. This instrument should replace all formerly used tools with one common assessment to be used with all populations and settings. As part of this redesign, family and caregiver needs should also be included in the survey tools. To fully operationalize this idea of integrated care, once an individual enrolls in services, a clear system of communication and information sharing among their case managers and care coordinators should exist. These linkages will help to ensure individuals with intellectual disability and with aging caregivers are truly served with holistic, person-centered service delivery.

To support this concept of person-centered care, case coordinators should broaden the scope of the information they collect to inform the ongoing development of a more comprehensive care plan. When participants within the waiver system meet with their case coordinators, questions regarding health and welfare are recorded. In addition, the case coordinators should initiate conversations and make observations about: (1) caregiver state of mind, (2) personal development in the client, (3) changes in the home make-up, (4) quality of environmental conditions and cleanliness, (5) foreseeable lifestyle changes, and (6) concerns about future care. These changes should be part of an objective assessment provided by the Office of Developmental Programs for all case coordinators to use when speaking with clientele. A further discussion on how to objectively assess family caregiver risk factors appears below.

While it is federally mandated that the state is not allowed to track the demographics of caregivers, case coordinators from the Department of Aging should ask these following questions.

- Has the caregiver reported any deaths, serious injury or other life changing events in their life, if so, record yes, if not, record no.
- Is the caregiver currently receiving assistance to deal with emotional concerns/difficulties: If the caregiver reports receiving assistance for emotional concerns/difficulties record yes, if not, record no.

Using questions similar to these will ensure that case coordinators have an accurate picture of their clients’ daily context.

**Addressing Family Caregiver Needs**

According to an annual study on LTSS conducted by AARP in 2009, unpaid caregivers in Pennsylvania provided an estimated $19.9 billion dollars in assistance. It is troubling that current strategic planning teams in the State of Pennsylvania neglect to acknowledge the valuable role that unpaid caregivers play in the system. Although it is not uncommon in any state for unpaid caregivers to represent a large proportion of the aide administered, as a state, Pennsylvania needs to do more to support the physical, emotional and financial health of these caretaking individuals.

The state of Washington has recognized that unpaid caregivers in their state contribute 80% of the system’s LTSS ($10.6B) every year. To both support caregivers in continuing to play this role and to prevent individuals from prematurely turning to Medicaid LTSS and moving into expensive residential care, Washington has adopted and fully funded a robust Family Caregiver Support Program (FCSP). These funds provide services such as respite care, home-chore assistance, and training to new caregivers. Based on an objective, evidence-based screening tool called the Tailored Caregiver and Assessment Referral System (TCARE), care coordinators in Washington assess the types of services
needed by each caregiver. This tool identifies an individual’s needs and categorizes their level of burden into high, medium, or low based on five domains: (1) relationship burden; (2) objective burden; (3) stress burden; (4) depression; and, (5) caregiver identity discrepancy. An individual will qualify for one of three funding tiers based on their initial TCARE screening: $300 per month, $500 per month, or full services. Every caregiver who completes the screening is eligible to receive the standard FCSP services. Those assessed as having a high level of burden are eligible for a full assessment, an individual consultation and care plan, and a higher tier of FCSP services.

In 2012, Washington’s state legislature voted to increase state funding for the FCSP by an additional $3.45 million, lowering the thresholds for full services in order to provide the “high tier” services to more families. An evaluation of the TCARE model under the expanded FCSP program shows that those individuals cared for by a family member who received support services under the expanded FCSP were 20% less likely to transition into Medicaid long term care and costly residential services in the twelve months following screening. Additionally, more of these care receivers were enrolled in Medicaid coverage prior to participation in the FCSP than the control group pre-expansion. Thus, in the long run caregivers who are provided with strong support services allow for less weight to be exerted on the Medicaid system as their loved ones are able to delay entry into expensive LTSS and live at home for longer.

In contrast, Pennsylvania’s caregiver support program, provided by the Department of Aging, is vastly underfunded and only serves a select fraction of unpaid, family caregivers. The programs in both states offer a similar form of services through their respective programs, yet large differences still remain when it comes to the depth and amount of supports. Under current program criteria in Pennsylvania, parental units and guardians caring for dependent adult children with a disability do not qualify to participate. Furthermore, the maximum funding limits for an individual do not exceed $200/month. Respite care was cited by every advisory board member the research team interviewed about caregiver supports as one of the most impactful forms of aide a system could provide. The individual funding limits have not increased in years and, unfortunately, the per person allotments do not stretch far in for family members in this day and age.

The final, yet very critical difference between the two programs relate to how one actually retains assistance under the FCSPs. Pennsylvania provides the option for caregivers to pick and choose where their funding goes and what type of services they need. Although the idea of personal choice here sounds appealing, it actually can be counterproductive because as humans we lack objectivity in assessing our own risk factors and far too often restrain from asking for help especially for our benefit. The caregiver support program as it stands now does not serve the full target population in need, and for those who do qualify to participate, it does not do enough. In order to truly attend to unpaid caregivers in Pennsylvania and save money for the state’s Medicaid program, expansions of the program need to occur.

Additional Improvements for the Strategic Planning Process

The current process for improving the state’s strategic plan focused the target population has many parts that are important and necessary. However, more could still be included within the plan.

Under BIP’s federal Funding Opportunity Announcement (FOA), the state is to administer a 12 month planning period that incorporates a collaborative partnership with all state agencies that represent or serve the interests of those with intellectual, developmental, and physical disabilities. These include the following offices within the Department of Human Services in Pennsylvania: the Office of Long Term Living, the Office of Developmental Programs, the Office of Mental Health and Substance Abuse, the Office of Income Maintenance, the Office of Medical Assistance Programs, and finally individuals with an ID/DD. During this planning period the state is to report to CMS on a quarterly basis the progress they have made in preparing for system-wide implementation of the three changes.
At this point in the process, the team has received criticism for what seems to be a lack of representative parties from the advocacy community, community providers and local nonprofits, as well as a self-representative body of consumers and individuals with developmental disabilities from across the state. In order to develop a truly user-friendly model that consumers across the state can take advantage of, the state needs to ensure these stakeholders are fully informed in a timely manner of the planning taking place. Furthermore, they should be given the opportunity to offer public input regarding the functional design and implementation of these initiatives.

**CRITICAL COMPONENTS OF THE FUTURE OF LTSS**

In addition to these efforts, several ongoing actions need to be implemented to provide the best services and program. Building a strong and inclusive strategic plan is not all the state should focus on.

The next step in fully operationalizing the state’s new policy directives is to create real, measurable goals for agencies to work toward at the state and county levels. These goals should inform the way the state allocates funding on an annual basis. Similarly, these goals should be driven by the data collected at the local and state offices. Each agency should be focus on increasing the quality and quality of services provided. As mentioned above focusing on the individuals as well as the caregiver can decrease overall needed funding.

Each year the Office of Developmental Programs receives a report conducted by the Quality Oversight Groups, part of ODP’s Quality Leadership Board that exist throughout the state. Five regions create a report by talking to participants, caregivers, and providers about the quality of services and life experiences through the programs offered by the state. These reports are looked over by the administration to ensure that their goals and objectives are being met so that appropriate changes can be made when needed.\(^{xxvi}\)

The annual reports done by the regional oversight groups are available to the general public only by contacting the office via phone and asking for one. The knowledge of this group is limited and is hard to come across for the average citizen; thus an electronic link should be provided on the ODP and OID website. This electronic publishing shows that the state is doing their best to ensure that the programs are meeting the goals driving them.

The state could also include information about the environment and caregivers, if that is not already included. Since the report was not able to be obtained, we are unsure if this is already being examined. However, if it is not, the assessment should ask pointed questions similar to the ones suggested above for the state’s quality management and targeted goals can be seen by looking at the state of Washington’s Department of Social and Health Services.

As seen above, Washington provides an intuitive visualization of their measurable objectives and the progress the state has made in reaching those goals. This information is easily accessible to the public, published directly on their site.
case coordinator towards caregivers, environments, and services being provided by nonprofits with the area.

**CREATING COMMUNITY CHANGE**

The next set of recommendations are focused on increasing connections and widening the community around the individual with intellectual disabilities and their caregivers. RICCs empower individuals with intellectual disabilities to be a leader in their community. Microboards create a network of committed individuals to help the caregiver. Over the long term, the effects of these programs are more support for the caregiver and less isolation for the individual and their family.

**Representative Community Coalitions**

Regional Inclusive Community Coalitions (RICCs) are coalitions throughout the state of Michigan led by an individual with a disability. They help those with disabilities become leaders of advocacy in their own community, while building confidence and learning critical information regarding policies that could affect their lives. This is done through trainings on self-advocacy and communication between each coalition and the Michigan Developmental Disabilities Council. Each RICC receives $4,000 yearly to pay for supplemental trainings that are deemed helpful to their specific coalition. This money is provided by the Michigan Developmental Disabilities Council, which is led by 21 Michigan citizens that are appointed by the Governor. Also, each RICC receives the support of a Regional Coordinator to coordinate events and communicate with the Council.

The most unique aspect of the RICCs is their relationship with the greater Michigan Developmental Disabilities Council. As mentioned previously, the Michigan Developmental Disabilities Council is made up of appointed members and they support the work of the RICCs. Also, RICCs have a direct relationship with the Council, which provides a feedback loop on a local level to a Council that is responsible for the entire state. This loop ensures that people with disabilities and their family members have a voice in the policies, programs, and services that affect their everyday lives.

RICCs speak to the concept of inclusion, in that they provide a method for individuals to become more involved in their community. The more included an individual with an intellectual disability is in their own life and their community, the more connections they will gain, the more empowered they will feel, and they will be better able to live a life not solely relying on their caregiver.

**Alternative Methods of Care**

Microboards are non-profit organizations that are created for the sole purpose of caring for an individual with intellectual disabilities. One of the main goals of Microboards is to foster community-based care. Just like a normal non-profit, a Microboard has a board of directors that is chosen by the legal guardian of the individual and typically consists of family and friends they trust. These individuals are given authority over a number of activities the Microboard does, such as paying for services provided to the individual. This allows others to assume responsibility for caring for the individual and provides the primary caregiver much needed assistance. The Microboard is able to pay for services given to the individual and can even apply for HCBS waivers, allowing it to become a service provider. It is not a form of guardianship and all final decisions rest with the legal guardian.

Microboards help aging caregivers in three main ways: by formalizing support, planning for care after the caregiver’s death, and decreasing isolation. Oftentimes individuals that had previously helped the caregiver can be drawn away with the business of their own lives, leaving the caregiver alone in caring for their loved one. Accepting a spot on a Microboard represents a binding commitment to help serve the individual with intellectual disabilities. It being binding means the primary caregiver always has an established group of people they can turn to for support.
One of the biggest concerns for parents with mentally disabled children is what will happen to their child after they pass away. Will they become a ward of the state? Can they trust others to care for them? A Microboard can help alleviate some of these concerns. The caregiver can be comfortable knowing that there are multiple individuals tasked with caring for their child after they pass way. If funding is available, then the Microboard can continue to pay for the same services the disabled individual received prior to the caregiver’s death. The Microboard could conceivably pay for housing if funding was available. By establishing a Microboard, there is still a group of individuals committed to helping the disabled individual even after the primary caregivers passing.

Caring for an individual with an intellectual disability can be an alienating experience. Many people will be unable to relate to the caregiver’s situation and the caregiver can feel increasingly isolated from friends and family due to the intense attention required to the disabled individual. Establishing a Microboard would help create a system of shared responsibility, ensuring that the primary caregiver is not alone in their situation.

Individuals are able to make Microboards in any state, but very few have been created in Pennsylvania. Many states have a non-profit that is tasked with helping individuals create Microboards and raising awareness about their existence. There is a Pennsylvania Microboard Association, but it does not appear to be active; the website does not list any meetings since 2011. Having a functioning Microboard-support organization at the county level is important since Microboards are difficult to set-up. The natural place to turn for assistance establishing a Microboard would be the Pennsylvania Microboard Association, but if they are inactive where will people turn to navigate the legal process?

Tennessee is often regarded as one of the states that has been the most successful in implementing Microboards. The Tennessee Association of Microboards receives funding from the state and there are over 60 active Microboards. The Director of the organization acknowledges that financial support from state and local agencies has been integral in their success. The Pennsylvania Microboard Association received one grant in 2005, but has not received any funding since. If Microboards are to be successful in Pennsylvania, then the Microboard agency would likely need financial support from the government to finance their programming.

We envision Microboards as a long-term, quasi-experimental solution. Microboards cannot be set up quickly and represent a significant commitment to all parties involved. Additionally, Microboards are unique in their operations and remain relatively uncommon throughout the US. However, we believe that they offer advantages no other care model can provide. The shared model of responsibility, the long-term planning, and the opportunity to personally tailor services are unparalleled. In order to move Microboards into the mainstream and make them user-friendly, we have come up with the following recommendations:

- Provide the Pennsylvania Microboard Association with state funds to help increase their operations
- Promotion of Microboards from government and non-profit agencies to help increase awareness
- Training sessions sponsored by non-profits on how to set-up Microboards
- Success stories from individuals who have significantly benefit from Microboards

**SUMMARY**

RICCs and Microboards are two unique programs that create lasting change for individuals with intellectual disabilities and their caregivers. RICCs help teach individuals to be self-advocates and allows them to have a voice in the system that manages a portion of their life. Microboards formalize commitments for caregiver assistance and ensure the caregiver is not alone. Together, these programs help widen the community around caregivers and individuals with intellectual disabilities.

System changes are also needed to create formal networks to support caregivers. Including these essential resources for caregivers in the strategic plan could allow for the state to save money in the long
run while providing services to those in need. The state should also see how to involve them in the planning process by connecting all stakeholders to the necessary resources via links on the relevant websites.

These overall changes will allow for Pennsylvania to continue their momentum towards creating a bright future for individuals with an intellectual disability and their caregivers. The state has made large strides towards creating a system that provides and supports individuals in need. The recommendations made will help the state fill some of the missing pieces.
PART VI: CONCLUSION

Pennsylvania has more elderly caregivers than the United States as a whole. Allegheny County is also experiencing an aging population, leading to the argument that the average age of caregivers will grow older as the population ages. As individuals age, caring for themselves becomes more complicated, let alone caring for an individual with intellectual disabilities. This leads to an increasing need for services targeted towards caregivers.

Cost and enrollment projections were completed to help quantify the future demand for services. Analysis showed that per person costs for both the P/FDS and Consolidated HCBS waivers are expected to increase on the state and county levels. The P/FDS and Consolidated waivers are expected to increase by 26% and 9%, respectively, over the next five years in Pennsylvania. For Allegheny County, the P/FDS waiver is expected to increase by 43% and the Consolidated by 9% of the next five years. The enrollment increases are steadier, with Allegheny County projected to have increases of 7.6% and 13.7% for the Consolidated and P/FDS waivers, respectively, over the next five years. Pennsylvania is expected to see enrollment increases of approximately 10% for both waivers over the next five years. These results indicate additional funding will be required to sustain the system at similar levels of care in the future. Allegheny County and Pennsylvania will also need to prepare for additional caregivers utilizing resources.

In order to improve the services offered to caregivers, Pennsylvania’s strategic planning process for intellectual disability services was examined. The Governor’s Commission on Long-Term Care was identified as a proposal that offers meaningful improvements to caregiver assistance. The No Wrong Door model helps make accessing information easier for caregivers by streamlining the connections between resources. Including caregivers in the Core-Standardized Assessment will ensure caregivers needs and situations are also given consideration in planning services for the individual with intellectual disability. Implementing the Governor’s Commission with caregivers included in the Standardized Assessment would help make caregivers job easier and also include them in the care planning process.

Other states were also reviewed to identify programs that were beneficial to caregivers. The State of Washington was identified as one such state due to a fully funded and well-developed Family Caregiver Support Program (FCSP). Five categories of caregiver needs are evaluated based on their burden level. Three tiers of funding are available to caregivers based on their identified need for assistance. It was found that caregivers who participated in Washington’s FCSP program were 20% less likely to transition into Medicare long term care. On the other hand, Pennsylvania has a poorly developed FCSP. Funding is capped at an amount less than the lowest available funding tier in Washington. Additionally, the program is only available to a fraction of caregivers. It is recommended that Pennsylvania improve services to caregivers by implementing a FCSP program similar to Washington’s.

To fill the gaps in long-term strategic planning, two additional recommendations were developed. First, state and county agencies should set measurable goals for themselves. These goals would be driven by data collection efforts on the part of each agency. Using this information, agencies can monitor their progress and understand what areas they need improvement in. Second, there should be more transparency on what oversight groups are finding. Pennsylvania has a Quality Oversight Group that speaks with caregivers and service providers about the quality of services being delivered by the state. They issue a final report that is difficult to get a hold of and not widely known. By making the contents of this report more transparent, other groups that work with intellectually disabled individuals could structure their services to fulfill some of the gaps the State has in their programming.

The final two recommendations touch on community inclusion for individuals with intellectual disabilities and their caregivers. Regional Inclusive Community Coalitions (RICCs) are networks of individuals with intellectual disabilities throughout the state of Michigan. These networks facilitate discussion between disabled individuals with the ultimate goal of helping them self-advocate. Bringing this program to Pennsylvania would help ensure that those with intellectual disabilities have an established community
and are able to assist one another. Microboards are non-profits that are created by the guardians of individuals with intellectual disabilities that help establish a network of committed individuals to help the primary caregiver. Because they are difficult to make, many states have Microboard associations to assist in their creation. However, Pennsylvania’s Microboard agency appears to be inactive and does not receive any funding from the state. Revitalizing the Microboard agency and providing it with adequate funding can help ensure this is a viable option in Pennsylvania.

Caregivers of individuals with intellectual disabilities face many difficulties throughout their lives. From determining what will happen to their child when they die to getting their child ready in the morning, each is fraught with challenges. Their commitment to their disabled child is commendable and the role they play in their lives is vast. Caregivers occupy an important role in our society and it should be the state’s role to give them the best services available. With caregivers expected to become older, and costs and enrollment projected to increase, there is ample need for Pennsylvania and Allegheny County to improve their services for caregivers. By focusing on improving long-term strategic planning on the State and County levels, as well as increasing community inclusion for individuals and their caregivers, Pennsylvania can become a champion of caregiver support.
APPENDIX I: TEAM INFORMATION

UNITED WAY OF ALLEGHENY COUNTY
United Way of Allegheny County is a change agent and efficient community fundraiser that improves lives by addressing critical community needs. By convening diverse partners and investing in programs and people to advance solutions, United Way creates long-lasting change and helps children and youth succeed, strengthens and supports families by promoting financial stability, ensures the safety and well-being of vulnerable seniors, assists people with disabilities, and provides information and referral sources meeting basic needs for residents of Southwestern Pennsylvania.

HEINZ COLLEGE, CARNEGIE MELLON UNIVERSITY
Carnegie Mellon University’s H. John Heinz III College was founded as the School of Urban and Public Affairs in 1968. The animating vision that led to the school’s founding was to bring a systems analytic approach (inspired by engineering and the mathematical social sciences) to the study of important questions of public interest.

In the years since the College’s founding, we have broken the traditional boundaries of the domain of the public interest to deeply explore deeply the impact of information technology on organizations, markets and societies. And we have persistently explored the ways in which we could make our educational programs more relevant and effective in their curriculum, in their delivery models, and in their degree of connection to external partners.

Unlike many graduate schools, we are not organized along academic departments. Faculty from our two schools -- the School of Public Policy and Management and the School of Information Systems and Management -- collaborate on instruction and research, an operating model we believe leads to innovation in research and a superior educational experience. Our strengths span the applied disciplines of empirical methods and statistics, economics, information systems and technology, operations research and organizational behavior.

Advisor: Professor Gordon Lewis
Professor Lewis has been with the Heinz College since its inception. He is one of the originators of the Systems Synthesis project and has guided many projects over the course of his career. He has worked in a variety of areas including incentives in welfare policy, the economics of day care, child support enforcement, organizational design, budget allocation procedures, and more. His Bachelors, Masters, and Doctorate degrees are from Stanford University. Due to his vast experience, we are privileged to have him as our guide through this process.

Brook Abitz
Brook is a second year MSPPM student at Heinz College. Prior to starting her graduate career, she was a Peace Corps Volunteer in Burkina Faso (West Africa) where she worked with a local women’s association on business planning.

Alexa Born
Alexa is a second year MSPPM at Heinz. Before coming to graduate school she was the Director of Education at 91.3fm WYEP in the Southside of Pittsburgh where she developed a variety of new programs for students of all ages.

Natalie Bucklin
Natalie is a second year MSPPM student at Heinz. Prior to coming to Heinz, she did analytic work for non-profits and commercial organizations in Chicago. Natalie currently works for Coro Pittsburgh as a Program Evaluator.
Matthew DiFiore
Matthew is a second year MSSPM at Heinz. His prior work experience is in political campaigns, including President Obama’s reelection campaign where he was a Field Organizer in Erie, Pennsylvania.

Meghan Jendusa
Meghan is in her second year of the M.S. Public Policy and Management program at Heinz College. Previous to starting at Carnegie Mellon, Meghan completed the Coro Fellows Program in Public Affairs in St. Louis, MO and worked for the St. Louis Regional Health Commission, a local non-profit aimed at reducing health disparities and improving access to health care for the uninsured and underinsured in St. Louis community.

Sara Taylor
Sara is a second year MSPPM student at Heinz. Prior to moving to Pittsburgh, she worked in nonprofit fundraising for several Seattle organizations. She also interned for the United Way of Allegheny

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