



## Background & Talking Points on Issues

### Residential and Other Opportunities

#### BACKGROUND

The development of new residential opportunities and other supports for people with intellectual and developmental disabilities is lagging far behind the increasing demand for them. This is particularly true for adults with developmental disabilities living at home with aging parents. Individuals, who in a former age would have been institutionalized, have remained with aging parental caregivers throughout their adult lives. Now many of these caregivers have lost their ability to adequately support their adult child with developmental disabilities due to their own age related disability. In 1998, the New York State CARES program was started to provide out-of-home community-based care to address the waiting list for service placements. New York State CARES has since been discontinued and the waiting list has increased to crisis proportions.

- According to available data compiled by David Braddock of the University of Colorado<sup>1</sup>, 64 percent of people with developmental disabilities in New York State, or 198,592 individuals, live with family caregivers. Of that number 54,309, live with family caregivers —usually parents—who are age 60 or older. Many of the family members in this cohort have provided loving care for many years but can no longer provide safe and appropriate care for their loved one. Many more family caregivers will lose their ability to provide for their loved ones in the future.
- New York State’s approved Home and Community-Based Services (HCBS) Waiver includes definitions for Priority I and Priority II individuals in need of service. Priority I includes many people at home, at imminent risk of homelessness, or inflicting harm on themselves or others. It also includes people (special populations) inappropriately placed in out-of-state facilities, nursing homes, and hospitals. Priority II individuals live under similar but slightly less desperate circumstances.
- Data on Priority I and II categories are not fully available or reliable. Extrapolating from available data, NYSARC estimates that there are roughly 6,000 Priority I and II individuals in immediate need of services across the state.
- Not all regional offices are fully staffed to effectively complete fundamental tasks such as determining eligibility, performing strength/need assessments, and matching individuals to appropriate services. This directly impacts the ability to place individuals with aging parents in needed out-of-home services.

<sup>1</sup> *The State of the States in Intellectual and Developmental Disabilities Emerging from the Great Recession*. Page 58. University of Colorado School of medicine, Department of Psychiatry, Coleman Institute for Cognitive Disabilities. Distributes by the American Association on Intellectual and Developmental Disabilities. 2015

## Residential and Other Opportunities (CONTINUED)

### TALKING POINTS

- People in critical need without placements: Do you know of Priority I or II people in need of services? If so, specifically note the number of such individuals with special emphasis on people living at home in need of out-of-home placements.
- Waiting time for critical services: Note the length of time these individuals have been waiting for appropriate services.
- Inability to use existing resources: Note the type and number of existing Residential and Day Services opportunities that cannot be accessed because of the Front Door, red tape, or other impediments.
- Future needs: Describe what you believe the demand will be for future placements, especially for people at home in need of out-of-home care.
- Point out that this year's OPWDD budget language requires OPWDD to provide data about critical needs; to eliminate barriers to obtaining critical services; and to establish a plan to increase housing alternatives for people in critical need of those services. The budget language was further reflected in the introduction of NYSARC bill (S.4180 by Ortt/A.6344 by Gunther) requiring data on Priority I and II individuals in critical need of out-of-home placements. Note instances in which these issues are still problematic as well as instances in which they have been or are being fixed.

### ACTION: Personal Stories are Critical!

- Personal stories that put a face on people and their families in need of out-of-home opportunities and other supports is our most important tool for making our case to the press, public officials, and to your local community. For example, highlight family caregivers who are in desperate need of either in-home or out-of-home support; provide details of their struggles; video and interview them for the NYSARC website, your own web page, for the press, and for legislators.

## Employment

### BACKGROUND

Few would disagree that less restrictive, integrated employment, which pays at least minimum wage, is ideal. However, that ideal is often out of reach for many people with developmental disabilities given the hard realities of the economy and their individual support needs.

Currently, OPWDD is engaged in a productive conversation with NYSARC and other providers and advocates about the future of workshops. While initially OPWDD appeared to make a commitment to close workshops, the Centers for Medicare and Medicaid Services (CMS) clarified that current workshop locations can remain open provided they meet Home and Community-Based Services (HCBS) setting requirements, including greater community participation and workforce integration. In response to CMS' clarification and arguments advanced as part of NYSARC legislation to require workshops to remain open (S.3893 by Young/A.5959 by Gunther), OPWDD commenced a dialogue on the continued operation of workshop locations. NYSARC is very encouraged by this dialogue which, if successful, will provide for the continued operation of facilities which have provided people with the longtime friends, trusted staff, and the opportunity to earn a paycheck in a safe and familiar setting. Workshops would also provide a safety net for people with disabilities to fall back on for employment should they not be able to find a job, or in the event that a job opportunity does not work out.

## Employment (CONTINUED)

### BACKGROUND (CONTINUED)

However, there is much work to accomplish in order to realize the promise of the Governor's Employment First policy. Employment opportunities for people with developmental disabilities are scarce, transportation to get them to work is often not available, supports are not sufficiently funded, and significant changes to reimbursement of supported employment will present many challenges.

In the face of these challenges, government must provide a leadership role in the development of employment opportunities for people with developmental disabilities. Additional resources must be brought to bear to provide the supports and employment opportunities people need. Employment opportunities for people with developmental disabilities are generally in short supply. Only twenty-two percent of working age people with cognitive disabilities are employed.

### TALKING POINTS

- Expand access to Transportation: Transportation is a major issue for employment. Describe current local transportation challenges, problems of getting to work, and what can be done locally to help with this challenge.
- Describe the employment supports you need, why, and what you need more of—people with developmental disabilities often need support to make their job performance acceptable. Describe the specific supports they require to perform a job. Describe existing shortfalls in the existing support system.
- Describe how having a reliable “safety net” is critical. This is not only for the person with developmental disabilities, but also his or her family.
- Describe the employment models that work best for the people you serve. Also, describe what you need to improve those models (i.e. small group settings) and what you need to make those models more readily available to more people.
- Describe the critical need for services to help people graduating from high school to transition into the workforce (e.g. vocational counseling, training). Describe the current need for these services and the likely future need. Describe what you need to make services better and what you will need to increase their availability.

### **ACTION: Personal Stories are Critical!**

- People should share personal stories about struggling to find jobs in the face of an acute job shortage for people with disabilities. They should note what resources would (e.g. transportation, training) enable them to succeed in the midst of these struggles.
- People should also share employment success stories and those factors that helped them to succeed. Individuals with successful workshop experiences should describe those experiences and include their recommendations for transforming and enhancing workshop settings.
- Families can share their vision for their loved one's employment. People with developmental disabilities and their families should discuss their aspirations and future career goals.
- In describing how you or your family member could benefit from competitive employment, urge your legislator to pass S.5805 by Senator Young/A.8111 by Assemblyman Santabarbara in the upcoming 2016 legislative session. This bill, initiated by NYSARC, creates a customized employment program in state government by reducing jobs to their simple component parts (i.e. paper shredding, answering the phone), each of which can be performed as a single, competitive job by people with disabilities.

### BACKGROUND

For people with developmental disabilities, their families and their friends, no employees are more important than the tens of thousands of Direct Support Professionals (DSPs) statewide.

- DSPs work long hours and provide support 24 hours a day, seven days a week. They have the responsibility to ensure that people with developmental disabilities are safe in their residences, lead fulfilling lives, and receive critical attention for complex issues. DSPs teach essential living skills, supervise daily activities, and assist with personal hygiene, meal preparation, and other tasks. They share responsibility for helping people manage their physical and behavioral health and often support the delivery of needed medical services in both day-to-day and crisis circumstances. It is physically strenuous work, often involving the lifting and moving of individuals who require such assistance.
- DSPs are responsible for providing services in a highly regulated environment that is closely scrutinized by State regulatory bodies. Mistakes can cause harm, so DSPs and their employers are held to the highest standards of accountability. Having such a great responsibility requires them to navigate a lengthy and complicated job application process, including a criminal background check.
- DSPs are some of the hardest working employees in the nation. Despite this, DSPs are often paid at, or just above, minimum wage.
- **Governor's minimum wage plan**—the Governor has a plan to provide a significant minimum wage boost to fast food workers. NYSARC supports increasing wages for fast food workers as part of a plan to increase wages for all low-paid workers.

However, the plan to raise wages for a targeted group of low-paid workers has the potential to undermine care for people with developmental disabilities. Nonprofit providers of services for people with developmental disabilities already are experiencing significant challenges recruiting and retaining critical staff due to an improving economy and tightening job market. Vacancies in critical DSP positions are becoming harder to fill. Fast food employers have always competed with developmental disability service providers for front line workers. A targeted wage boost for fast food workers would give the fast food industry an enormous competitive advantage and exacerbate recruitment and retention challenges.

We support the hard working employees of the fast food industry. But our DSPs, who are responsible for supporting the lives of so many special New Yorkers, deserve attention as well. Only increasing the minimum wage rate for one sector creates a dangerous distortion in the labor market and will have a dramatic and negative impact on the people NYSARC supports.

### TALKING POINTS (Chapters/Executive Directors should use their discretion to determine whether or not it is appropriate to use this data):

- DSPs perform difficult but rewarding jobs for relatively low wages: Explain this as noted above and per your own observations.
- Improving job market brings recruitment and retention challenges: Are vacancy rates and turnover rates in your Chapter reflecting an improving job market? If so, use whatever data you have to demonstrate this.
- Impact on care: How have turnover and vacancy issues impacted care? Are your employees less experienced given higher turnover? Cite specific examples to illustrate the potential impact on care.

## Wages (CONTINUED)

### TALKING POINTS (CONTINUED)

- Recommend a necessary adjustment to reimbursement rates for State funded human service providers to enable them to increase the wages of DSPs and to manage recruitment and retention issues.
- Urge your legislator to advocate for passage of NYSARC initiated legislation (S.5838 by Ortt) which will mitigate minimum wage related challenges in two ways: (1) by increasing reimbursement paid to human service providers to reflect direct and compression costs resulting from an increase in the minimum wage, and (2) should the Commissioner of the NYS Department of Labor order an increase in the minimum wage for a specific industry, the Commissioner must also recommend a necessary adjustment to reimbursement rates for State funded human service providers to enable them to manage resulting recruitment and retention issues.
- Impact of recruitment and retention challenges on 24-hour programs: For example, can you keep the awake/overnight shift filled?
- Overtime: How much overtime are you using to fill vacancies? What is the impact of overtime on the effectiveness of staff that work longer hours?
- Use of contract staff: Are you forced to use contract/on-call staff who are unfamiliar with the people they serve?
- Where are DSPs going? Do you have exit interview data demonstrating the threat that other industries pose by competing for our DSPs (i.e. the food service/fast food industry)?
- Wage compression and the minimum wage: Make the case that a minimum wage increase must take into account compression (i.e. do you think morale will be negatively impacted when senior staff suddenly find new hires making as much or close to what they do?). Describe the likely impact on care.
- Health and safety impact: What is the impact on health, safety, and quality of life of all of the above?

### **ACTION: Personal Stories are Critical!**

- Personal stories of families and people with developmental disabilities whose well-being depends on DSPs are critical. For example, what do families depend on DSPs to do? How would these families and their loved ones be affected if DSPs they've come to trust leave for higher paying jobs?

These stories should include personal stories from DSPs who are struggling to make ends meet for themselves and their families. Managers and families can tell stories about good DSPs who have left for higher paying jobs and what that has meant to the people they formerly served.

## Preschool

### BACKGROUND

Children with developmental disabilities aged 3 to 5 are served by Chapter 4410 preschools. Many of these children have significant special needs including autism, severe medical issues, and intellectual and other developmental delays. Many reside in households at or below the poverty line. Others may be recent immigrants with limited English language proficiency.

- All families, however, share a common goal: They want their children to become healthy, happy, independent, and productive individuals. That is the mission of our 4410 preschools. This is exactly why parents make the decision to send their children to 4410 preschool programs statewide.
- The efficacy of preschool intervention has been repeatedly confirmed by studies. This understanding has led to a proposal by the mayor of New York and others to expand Universal Pre-kindergarten.
- Despite this consensus, the 4410 preschool program is threatened with collapse. Despite rising costs, preschools have not received a growth factor in six years (nor are preschools allowed to retain reserve funds for contingencies like capital repairs). The rate methodology for reimbursing preschools pays only 94 percent of allowable cost and less of actual costs. If tuition funds are saved, they are recouped by State Education Department (SED) through retroactive rate cuts to the preschool program.
- NYSARC operates 19 preschools. Half of these programs will close their doors within the next two years unless an adequate growth factor is provided. While a 3.1 percent growth factor has been recommended by SED, it has not yet been approved by the Division of the Budget. Even if it is approved, the 3.1 percent growth factor is insufficient to prevent many preschools from closing their doors.
- Chapter 4410 preschools need a commitment from the State to provide adequate funding in order to provide some of New York's most at-risk children a chance for a life of independence and fulfillment.

### TALKING POINTS

- Inadequate pay has reduced our preschools to public school training programs: Has your preschool effectively become a training program for public schools as your teachers leave to take public school jobs offering higher pay? If so, make your case using data at your disposal.
- Funding and recruitment and retention: Is the lack of adequate funding hampering your ability to recruit and retain qualified professional staff? Again, use any available data.
- SED reconciliation process: Describe how the SED reconciliation process hampers your ability to provide services.
- Impact of no growth factor on services: Describe how the lack of growth factors hampers your ability to provide services.
- Impact on quality: Is there an impact on the quality of preschool education attributable to all of the above? Can you devote all the time and effort required to the children in your preschool?
- Needy children who can't be served: Are there very needy children whom you cannot serve for lack of resources, teachers, and appropriate classroom space?

### ACTION: Personal Stories are Critical!

Families who have had their children helped by our preschools should tell their stories. Specifically, these might include stories about children who have attended your program and then gone on (been declassified) to public school. Especially effective are testimonials from legislators or other public officials who have family members who have been served in your preschool.

## Transitional Services

### BACKGROUND

- Specialized transitional services are critical to move people with developmental disabilities from one setting to another to meet life's changing circumstances.
- For example, people graduating from high school must find a way to move onto the new world of work and careers. Persons with aging caregivers may no longer be able to continue living at home and need to find a new place to live, recreate, or work.
- Too often there are either insufficient services to make this transition or there are barriers to obtaining services even when those services exist.

### TALKING POINTS

- Budget language required OPWDD to address the lack of information about the level of need and appropriate transitional alternatives and services for people in need of services, especially those people living at home. Make the case that this information/data is critical if families are to advocate for services that meet their needs.
- Budget language also addressed the critical need to address barriers to services such as a Front Door policy which has often not worked as intended. Cite specific examples of how and why the Front Door must be improved, where it doesn't work, and where it does work.
- The transition from school to work is a major change for anyone, with or without a disability, and, especially for people with developmental disabilities, requiring critical services such as vocational counseling, vocational rehabilitation, and employment supports. Describe why those services, in addition to others you believe are helpful, are so critical.

### ACTION: Personal Stories are Critical!

- People should share stories about their frustrations with the Front Door and other obstacles to gaining appropriate services which are necessary to transition between life's changing circumstances. Specifically describe instances in which the Front Door hasn't worked but also instances in which the Front Door has been improved. Describe other instances in which the service system has worked and not worked to provide access to services such as out-of-home placement, crisis intervention, out-of-home respite, in-home supports, and other services which may be critical as an individual enters a transitional period of his or her life.
- Families and their loved ones with disabilities should share stories about the challenges they face transitioning from school to work. What services are and are not available to them? What improvements and additional services are most in need? Specifically, what has helped or hindered the move from the public school system to the OPWDD services system? Assessment services, vocational rehabilitation/counseling, supported work, vocational training, and various therapies such as speech, hearing, etc., may be necessary to assist in the transformational phase of life.