Alliance for the Betterment of
Citizens with Disabilities

Empowering People: Providers Shaping Policies

THE POWER OF RELATIONSHIPS
Getting to Know and Working with Your Elected Officials

ABCD Advocacy Toolkit

Why?

Agencies should build relationships with their elected officials to influence policy, secure funding, raise awareness and increase collaboration. It is an ongoing process.

Who?

Agencies should build relationships with all their elected officials who represent their towns and cities where they have programs, services and an administrative office. By "all elected officials" we mean local, county, state and federal representatives.

Local Officials: via the internet "(Town Name) New Jersey Government." Look for list and contact information of elected officials.
County Officials: via the internet, "(County Name) New Jersey Government." Look for list and contact information of elected officials.
State Legislators: https://www.njleg.state.nj.us/legislative-roster
Member of Congress: https://www.house.gov/representatives/find-your-representative
Senator Booker: www.booker.senate.gov
Senator Kim: www.kim.senate.gov

How?

Visit them in their offices, welcome them to your sites where they can see what you do and meet the people who receive and provide services and support, invite them to your events, and include them in your distribution lists.

- Know where the elected official stands on issues relevant to your agency. Consider how your work compliments their goals for the broader community.
- Don't use jargon or complex terms. You are the expert on I/DD, EI, Medicaid, etc.; chances are, they are not.
- Keep the topics to one or two; don't overwhelm them with information. You won't need to, because you will be in regular contact with them and their office from now on.
- If you don't know the answer to a question, tell them that you will get back to them. Make sure that you get back to them on timely basis with the information.

- If you meet with staff instead, know that they are trusted advisors to their bosses. For federal officials, staff are often issue experts. Typically, these meetings last longer and are more detailed about the issues.
- We will state again; you are an expert.
- Be a resource. Be sure to offer your help and assistance to the elected official and their constituent service staff. Consider extending this to all human services type questions. Chances are you might know more about the service system than they do (especially if they are new). Their calls should go directly to you or someone in the executive suite.
- Be a volunteer. This is mainly for the county government because they have human resource departments and related committees. Your agency should be at the table on those committees.
- We will state again; you are a resource.
- Include them on all or most of your communication lists. Invite them to all events, especially those occurring in their district. At these events, be sure to recognize them and invite them to speak (you should ask them if you can invite them to speak ahead of time).
- When visiting, leave written information about your agency and any policies discussed.

Fact Sheets

Economic Growth Trends.

An overview of why in calculating the annual state budget, the use of economic growth trends for inflation and increased costs for all DDD Community Providers and Early Intervention Providers is important.

Home and Community Based Services

An overview of optional Medicaid services for individuals with intellectual and developmental disabilities and on the possible impact of federal HR1 on the community.

Fee For Service Delivery System

An overview of the impact of the transition from contract based to FFS delivery system. Specifically, the complexities of and required product overhead in FFS.

Additional ABCD Policy Papers

Additional papers can be found on our website at www.abcdnj.org/advocacy and include policies on preventing ANE, aging in place, cameras in group homes, Central Registry statute, day habilitation virtual/transportation/clinical services, Department of Early Childhood, DDD oversight system, informal caregiver support, informed consent, managed care, mental health services, NJCAT, remote supports, and unlicensed group homes.

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Uptrends Must Include Inflation and Increased Costs

The New Jersey Division of Developmental Disabilities (DDD) annual budget request to the Administration is based on growth algorithms. In FY 25, 26 and 27, DDD requested and received additional funds to cover updated growth trends for the expanded number of individuals receiving DDD community services and for the shifts in consumer spending patterns to more expensive goods and services. Which begs the question, to maintain ongoing access to community programs for individuals who are currently and wish to remain enrolled, why doesn't DDD include inflation and increased costs for all DDD Community Providers in the uptrend?

Inflation is no friend to human services

Inflation is an economy-wide sustained trend of increased prices which represents how much investments lose their real value from one year to the next. When the government doesn't meet inflation and increased costs with an investment of equal value in Medicaid providers' fixed rates, the provider struggles to cover rising operational costs and facilities maintenance, retain staff, and meet the growing needs of individuals and families who rely on their services. The government must recognize that DDD Community Providers are also businesses. [1]

DHS has a fiduciary responsibility to all individuals with I/DD

In the current policy, access and choice are increased on one end while eroded on the other. But the state has a fiduciary responsibility to all IDD not just to those with more expensive taste in services. Sustaining and maintaining the health and viability of our current system to prevent it from failing or declining must also be considered in DDD trend calculations.

Inflation must be a constant factor in all budget trends, deliberations and requests. Therefore, it is imperative that an annualized[2] across the board Cost of Living Adjustment[3] for all Division of Developmental Disabilities Community Providers be established.

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[1] The state of CT recently passed legislation to require that non-profit state funding will increase with inflation every year, requiring approval each year by the legislature.
[2] Annualized increases are required to prevent forgoing federal CMS matching dollars and destabilizing the industry.
[3] The purpose of a COLA is stabilization in the face of cumulative inflation.

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Inflationary Increase for Early Intervention Providers

Early Intervention (EI) provides life altering therapies to infants and toddlers, ages 0-3, with developmental delays and disabilities. The goal of this intervention is to minimize and prevent permanent disability.

EI providers receive fixed rates from the Department of Health (DOH) for the provision of their services. Because these providers are also businesses, when the government doesn't match the inflation rate with an investment of equal value, providers struggle to cover rising operational costs, retain staff, and meet the growing needs of infants, toddlers and their families for EI services.

Shortages of qualified workers is a pervasive problem across health and human services. Low compensation is not the only, but it is certainly a major factor. Recent administrations have worked hard to ensure that our workforce is well supported, trained, and compensated.

DOH must continue to support DOH staff and EI providers in this effort, so that children do not "face delays and interruptions in accessing the services they need to succeed. "[1]

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[1] Ibid, page 6.

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The Fee for Service Delivery System

The transition from contract based to the Fee for Service (FFS) delivery system represented a shift from moderate to high risk and responsibility for the provider agency. Improving freedom of choice for the individual meant providers had to accommodate unpredictable cash flows while upgrading staff skill sets and overcoming cultural barriers in the community.

Under FFS unpredictable cash flow stems from and results in:

- Competition between agencies to fill programs requiring investment in satisfaction surveys, marketing, advertising, sales, and service development.
- Payment made after service is provided, documented, reviewed and claimed requiring investment in revenue cycle management to ensure clean claims and optimized revenue.
- Liability stretched out into the future requiring investment in documentation and billing, internal audits and inspections, corporate compliance, infrastructure, quality control, electronic medical records and good governance.

Under FFS the mission is to enable individuals to thrive in the community using the humanistic, person-centered model of providing supports and services. This demands:

- Additional skill sets from direct care staff such as adaptability, confidence, spoken and written communication skills, competency development, innovation, knowledge and leadership requiring investment in education, training, technology, and oversight.
- Agency progression from supporting individuals' participation in to their inclusion and integration into the community requiring creative, innovative and adaptable ways and means to bridge the divide.

Under FFS, general and administrative expenses ensure day-to-day operations run smoothly, efficiently and effectively, supports infrastructure, ensure compliance and enable strategic growth.

Lastly, our publicly funded person-centered business model is humanistic and inefficient - vulnerable to profits and losses and to political and social critique necessitating the need for good executive leadership.

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Home and Community Based Services for Persons with Intellectual and Developmental Disabilities

Home and community-based services (HCBS) [1]are optional Medicaid services which provide opportunities for individuals with intellectual and developmental disabilities (I/DD) to receive person driven services in their own home or communities rather than in an institution. A wide range of services are available which include but are not limited to assistance in activities of daily living, community engagement, employment supports, transportation, habilitative therapy, respite, and assistive technology.

HCBS is funded through Medicaid which operates as a state/federal partnership. States set the payment rates, and the federal government provides matching funds which are used to reimburse providers for the services that they provide to individuals with I/DD. The reimbursement rate must cover staff wages and benefits, operational costs, program development and facilities management – every expense necessary to provide supports and services to individuals with I/DD.

Insufficient Medicaid funding for HCBS means providers face staffing shortages and are at risk of program closures which will limit the choices of people with I/DD, leaving some to remain on lengthy waitlists or be forced into institutional settings.

Though many of the specific provisions in federal HR1 do not directly impact I/DD, it is reasonable to expect the magnitude of the reduction in funds will put a broad strain on New Jersey's Medicaid budget.[2] In light of this concern, many states are considering cuts to optional services like HCBS.

We laud Governor Sherrill, her Administration, and the New Jersey Legislature for their continued commitment to supporting and expanding the opportunity for individuals with IDD to live and thrive in the community through the HCBS CCP/SP Waiver, as evidenced by the FY 27 Budget.

See the value HCBS has had on individuals, families and staff, through their stories in ABCD's Defending the Achievement Campaign at www.abcdnj/advocacy/

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[1] In NJ, HCBS for the I/DD population are entitled the Community Care Program and Supports Program (CCP/SP). For purposes of this paper when we use the generic term HCBS it is meant to represent CCP/SP for the I/DD population.

[2] Assuming that NJ will be able to prevent half of the people enrolled through Medicaid Expansion, which receives a larger federal match then other Medicaid programs like ABD, from losing their coverage due to work reporting requirements and bi-annual reenrollment and assuming there are no additional sources of revenue and all divisions will be equitably treated, ABCD estimates a possible reduction of 4.5% for HCBS services.

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