

# How Self-Advocates, Parents, and DD Network Partners are Working Together to Change Disability Policy for the Better



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# How to Educate Your State Legislature to Make Change

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INSTITUTE FOR COMMUNITY INCLUSION  
*promoting the inclusion of people with disabilities*



# What We Will Cover

**Introduction**

**How to find your legislators**

**Build a relationship**



**How to educate them**

**How to make a difference**

**The Ask**

# Find your Legislators

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Google Search

I'm Feeling Lucky

Picture of google search website.

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# Find your Legislators

<http://www.wheredoivotema.com/bal/myelectioninfo.aspx>

The screenshot shows the website for William Francis Galvin, Secretary of the Commonwealth of Massachusetts. The header includes a portrait of Galvin, his name, and the state seal. A navigation bar contains links for HOME, DIRECTIONS, and CONTACT US, along with a search box. A sidebar on the left lists various services, with 'Elections and Voting' highlighted. The main content area is titled 'Elections and Voting' and features a section for finding election information. This section includes a list of instructions: entering a residential address, a note that the address must be in Massachusetts, a link to village names, and a note that required fields are marked with an asterisk. Below this, there are three numbered steps for entering a street address: 1. Street number (37), 2. Street name (Park), and 3. Street suffix (RD). A final step requires providing a city or town or zip code, with a dropdown menu for city or town.

**William Francis Galvin**  
Secretary of the Commonwealth of Massachusetts

HOME DIRECTIONS CONTACT US Search the Secretary's website Search

Citizen Information Service  
Commonwealth Museum

Corporations

**Elections and Voting**

Lobbyist

Archives

Massachusetts Historical Commission

Public Records

Publications and Regulations / Bookstore

Registry of Deeds

Securities

State House Tours

Records Center

Regional Offices

## Elections and Voting

### Find my election information

**To find your election information:**

- Enter your residential address.
- This address must be in a city or town in Massachusetts.
- If you live in a village, view list of [village names \(opens in new window or tab\)](#) to find the city or town name for your village.
- Required fields are marked with an asterisk (\*).

**\* Required: Enter your street address in 3 separate boxes**

1. Your street number (numbers only):

2. Your street name:

3. Select street suffix:

**\* Required: Provide a city or town, or your zip code**

Your city or town:

Picture of Massachusetts election website.

## Your elected officials are:

Statewide office holders for the Commonwealth:

Governor: [CHARLES D. BAKER](#)

Lieutenant Governor: [KARYN E. POLITO](#)

Secretary: [WILLIAM FRANCIS GALVIN](#)

Auditor: [SUZANNE M. BUMP](#)

Treasurer: [DEBORAH B. GOLDBERG](#)

Attorney General: [MAURA HEALEY](#)

U.S. Senator: [ELIZABETH A. WARREN](#)

U.S. Senator: [EDWARD J. MARKEY](#)

District Representatives:

Congressional: [KATHERINE M. CLARK](#) -- [FIFTH DISTRICT](#) [View map](#)

State Senate: [KAREN E. SPILKA](#) -- [SECOND MIDDLESEX & NORFOLK DISTRICT](#) [View map](#)

State Representative: [JACK PATRICK LEWIS](#) -- [SEVENTH MIDDLESEX DISTRICT](#) [View map](#)

Governor's Council: [ROBERT L. JUBINVILLE](#) -- [SECOND DISTRICT](#)

District Attorney: [MARIAN T. RYAN](#) -- [NORTHERN DISTRICT](#)

Picture of Massachusetts website listing all elected officials.

# Mass.gov

THE 190TH GENERAL COURT OF THE  
COMMONWEALTH OF MASSACHUSETTS



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[State House](#)

Representative  
★ **JACK LEWIS**  
Democrat - 7th Middlesex

Search the Legislature...



✉ [Jack.Lewis@mahouse.gov](mailto:Jack.Lewis@mahouse.gov)

STATE HOUSE

24 Beacon St. [↗](#)  
Room 443  
Boston, MA, 02133

Phone: 617-722-2460

[Bills](#)

[Committees](#)

[District](#)

[Sponsored](#) | [Cosponsored](#)

190th (Current) ▾

BILL	Docket	BILL PINSIP/TITLE
★ H.100	HD.1883	By Mr. Lewis of Framingham, a petition (accompanied by bill, House, No. 100) of Jack Lewis and others for legislation to establish a system for tracking the unmet service needs of persons with developmental disabilities, children, families and

## MOST POPULAR BILLS

★ S.3 An Act making appropriations for the fiscal year 2018 for the maintenance of the departments, boards, commissions, institutions, and certain activities of the Commonwealth, for interest, sinking fund, and serial bond requirements, and for certain permanent improvements

★ H.3600 An Act making appropriations for the fiscal year 2018 for the maintenance of the departments, boards, commissions, institutions, and certain activities of the Commonwealth, for interest, sinking fund, and serial bond requirements, and for certain

Picture of Massachusetts website of State Representative Jack Lewis.

# Let Your Representatives Know What You Think

- Telephone
- Letters
- Email
- Office Hours
- State House Visit



Picture of woman entering information on her cell phone.



# Have Your Legislator Know You

**Welcome to our world**

**Have them understand family support**

**Invite them into your homes**

**Invite them to your events**

**Get involved in their campaigns**



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# How to Speak to Your Legislator

- Politicians are people too
- They have feelings
- Don't be intimidated
- Tell your personal story
- They will pay attention
- Don't overwhelm them
- **THANK THEM!**



Cartoon of Snoopy  
hugging a small bird

# Bring Something to Leave with Them

- Make it easy for them to act
- Single Page
- Have your name and contact information on it

# Bring Something to Leave with Them

- Have the bill number or line item of budget request
- Include a brief summary of the item
- Provide a copy of the bill

HOUSE . . . . . No. 1898

By Mr. Saunicandro of Ashland, petition of Tom Saunicandro and others relative to establishing self determination for persons with disabilities. Mental Health and Substance Abuse.

The Commonwealth of Massachusetts

PETITION OF:

Tom Saunicandro	Barbara A. L'Esperance
John W. Schick	William Ledigas
David B. Sullivan	Bonnie Dean
Frank J. Sotnik	John P. Frosio
Robert L. Rice, Jr.	Glenn L. Fox
Matthew C. Patrick	Christina E. Croonen
David Paul Lindey	William N. Bowerhager

In the Year Two Thousand and Seven.

AN ACT TO ESTABLISH SELF DETERMINATION FOR PERSONS WITH DISABILITIES.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

1 Chapter 18B of the General Laws is hereby amended by inserting  
2 after section 18 the following section:

3 Section 19.—

4 (A) The department shall develop recommendations for the  
5 implementation of a self-determination model of funding services  
6 and supports that provides the ability for an individual receiving  
7 services and supports to personally control, with appropriate assistance,  
8 a targeted amount of dollars; the model shall include, but is  
9 not limited to, the following:

10 1. The ability to establish an individual rate or budget for each  
11 person;

12 2. Mechanisms to ensure that each participant has the support and  
13 assistance necessary to design and implement a package of services  
14 and supports unique to the individual;

Picture of printed legislation.

# Inside/Outside Strategy

- Who is the decision maker?
- How do we get them to support us?
- How do we mobilize?



Two men, one with Down syndrome, having a conversation in a historic looking office.

# Organize an Event at the State House

- Pick Priority Issues
- Day on the Hill, Lobby Day
- Awards Event
- Breakfast or Lunch Event
- Give Something Away



Many women in blue T shirts on staircase in state house.

# Vote!



Woman standing at voting booth with American Flag behind her.

# Conclusion

**Find your legislators**

**Build a relationship**

**Educate them**

**Involve Everyone**

**Work with them**

**Self Advocacy is important**

**Work to change the system**





# Allies in Advocacy



# Our Mission

Washington State Allies in Advocacy (Allies) is an activist organization whose mission is to improve the lives of all people with developmental disabilities (DD). We are governed and staffed by people with DD. We advocate for policies and programs in all aspects of society that increase the power of people with DD to make the decisions to live the lives we choose, the ability to access all the resources available to everyone else, the opportunities to build wealth and have an equal say in our local, national and international communities.

# Mission Continued

We believe the concerns of people with DD are often the same as many others who are trying to break down social and community barriers. We are committed to building partnerships to fight for common concerns.

We believe all people with DD should be free from ableism and other forms of discrimination, be treated as equals not only in word but through the true exercise of power and have the same opportunities in our lives that are available to our neighbors.

# Who we Are



A picture of the Allies in Advocacy Coalition in  
2013

# Our Start

- ▶ 2012
- ▶ Self Advocacy Summit in Seattle put on by Administration on intellectual and Developmental Disabilities and The Administration for Community Living.
- ▶ The Seattle Summit was one of many in the Country
- ▶ Self advocates and partners came from multiple states came together to promote self advocacy.
- ▶ Washington State Summit team was led by self advocates from multiple organizations.
- ▶ Our focus was to improve the lives of people with developmental disabilities

# Why we Continued

- ▶ We wanted to change the power dynamics in our state.
- ▶ We wanted more people with developmental disabilities to have more leadership opportunities.
- ▶ We wanted people with developmental disabilities to have more choice and control over their lives.
- ▶ We wanted to bring more power to self advocacy organizations.
- ▶ We wanted to create a values statement that talks about our rights.
- ▶ After two years this values statement became .....

# A Proclamation for the Dignity and Rights of all Human Beings

The proclamation has the following key components

1. We have the right to grow and develop to our full potential
2. We have the right to live free from abuse, neglect and exploitation
3. We have the right to access all aspects of our communities.
4. We have the right to make any and all decisions that affect our lives

# Proclamation Highlights Continued

5. We have the right to be treated with value and respect like all human beings.
6. We have the right to lead full meaningful lives.
7. We have the obligation to help others as they learn and fight for these rights.

The Proclamation was written for all Human Beings including people with disabilities.



# Allies in Vancouver



A photo of Allies members presenting at a 2015 Conference in Vancouver about the Proclamation

# Equal Partners Interstate Congress (EPIC)

- ▶ 2014-2017
- ▶ Partnership between Nevada, Idaho, Wyoming, Alaska
- ▶ Allies provided technical support to EPIC states and helped put on two Summits
- ▶ Goal 1: Increase Self Advocacy involvement in each state
- ▶ Goal 2: Provide EPIC states money, so they could build the infrastructure possible to sustain their self advocacy organizations.
- ▶ Goal 3: Start the conversation about creating a 4th Developmental Disability Network Partner headed by self advocates dedicated to promoting the Civil Rights of People with Developmental Disabilities.

# Allies 2.0

- ▶ 2017-Future
- ▶ Allies became the 4th Network Partner in Washington State
- ▶ We participate in quarterly meetings with the other three partners
- ▶ We work with our partners on a variety of issues including stopping abuse and neglect, eliminating sub minimum wage practices and increasing people's access to assistive technology.
- ▶ We became a State Non Profit
- ▶ We are working on federal paperwork, so we can become a federal non profit.

# Why Allies? Why a 4<sup>th</sup> Network Partner? Why Now?

We believe a 4<sup>th</sup> Network Partner is important now because:

1. People with developmental disabilities deserve to be equal partners with power in the disability movement.
2. Self Advocates are the best ones to empower others with developmental disabilities to take charge of their lives.
3. Self Advocates must be at the table when changes to policies and programs happen.
4. Self Advocates need to take the lead on making our communities more inclusive.

# Allies plans for the Future

1. Stop subminimum wage practices in Washington State
2. Make sure all communities in Washington State are open and welcoming to people with developmental disabilities.
3. Work with our state Developmental Disability Ombudsman to eliminate instances of abuse, neglect or exploitation.
4. Work to empower people with developmental disabilities to live full meaningful lives.
5. Work with other states to officially create a 4<sup>th</sup> network partner.

# What You Can Do

- ▶ **For Self Advocates:** Stand up and take more leadership in the disability movement.
- ▶ **For Families:** Support the self advocacy movement as it grows. We want to work hand in hand with families to make our lives better.
- ▶ **For Network Partners:** Support self advocates by provide technical assistance to them and find ways for them to assist your program.
- ▶ **For National Leaders:** Support and advocate with us for a 4<sup>th</sup> Network Partner.

# Contact

Shawn E. Latham

Independent Living Coordinator, Center for  
Independence

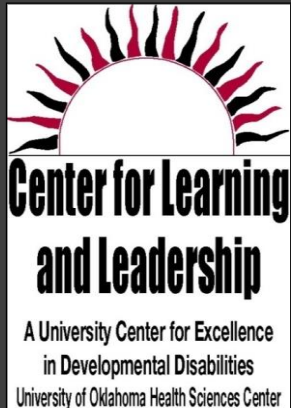
Chair, Allies in Advocacy

[admin@alliesinadvocacy.com](mailto:admin@alliesinadvocacy.com)

253-304-5762

<http://www.alliesinadvocacy.com>

# OKLAHOMA DD NETWORK PARTNERS THE JOURNEY FROM KEYS TO CAUCUS



Wanda P. Felty

Community Leadership and Advocacy Coordinator  
Center for Learning and Leadership, Oklahoma UCEDD  
Family Faculty, OKLEND

2018 AUCD Conference

We ALL Belong Here! Achieving Inclusive Communities



# DD Act Partners in Oklahoma

- Oklahoma Developmental Disability Council
- Oklahoma Disability Law Center
- The Center for Learning and Leadership/UCEDD



Oklahoma Developmental Disability Council Logo



Oklahoma Disability Law Center



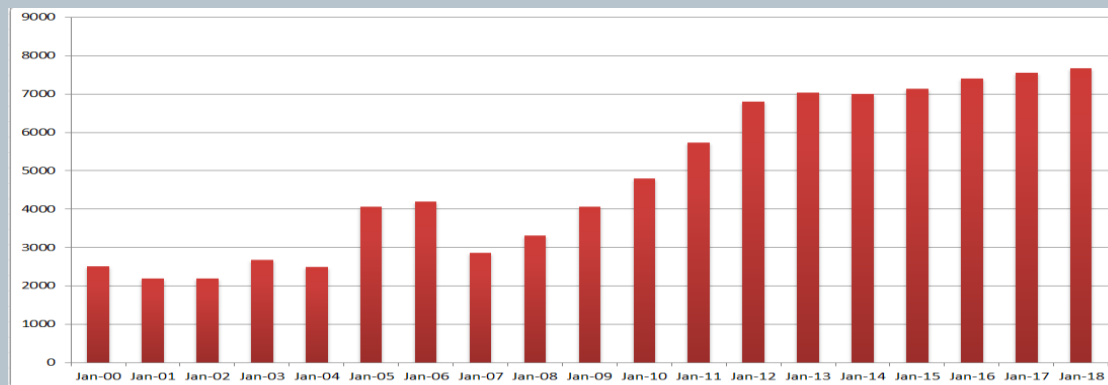
Center for Learning and Leadership / UCEDD

# DD Act Partners and Family Leaders

- Oklahoma Developmental Disability Council
  - Erin Taylor, Adult Advocacy Coordinator and Public Policy
    - Mother of Five
    - Youngest son has developmental disabilities
- Oklahoma Disability Law Center
  - RoseAnn Duplan, Policy and Planning Specialist
    - Mother of three
    - Middle son has developmental disabilities
- The Center for Learning and Leadership/UCEDD
  - Wanda Felty, Community Leadership & Advocacy Coordinator
    - Mother of three
    - Middle daughter has developmental disabilities

# Start with the Basics

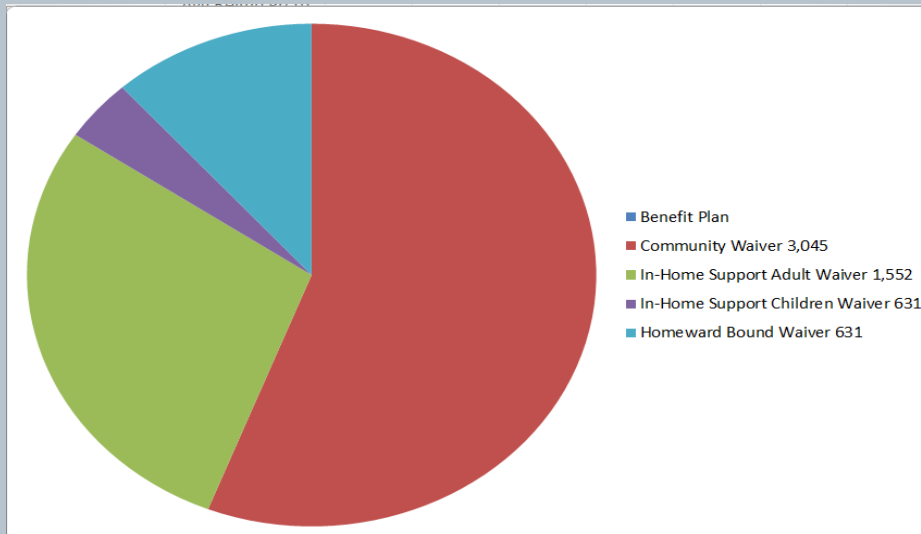
- What is the issue?
  - ▣ Limited access to supports or services for people with developmental disabilities



Jul-00	Jul-01	Jul-02	Jul-03	Jul-04	Jul-05	Jul-06	Jul-07	Jul-08	Jul-09	Jul-10	Jul-11	Jul-12	Jul-13	Jul-14	Jul-15	Jul-16	Jul-17	Jul-18
2504	2187	2187	2683	2494	4064	4204	2860	3314	4060	4805	5737	6810	7044	7011	7139	7405	7560	7672

# Start with the Basics

- What is the issue?
  - ▣ Limited access to supports or services for people with developmental disabilities



<b>Benefit Plan</b>
Community Waiver 3,045
In-Home Support Adult Waiver 1,552
In-Home Support Children Waiver 631
Homeward Bound Waiver 631
<b>Total Receiving support 5,384</b>

# Keys to the Waiting List

- Grassroots – old fashion advocacy
- Family Members and Self-Advocates  
“Key the Capitol”



250 Keys on a ring with a tag to Representative Dunnington



RoseAnn Duplan with her two kids and one other self-advocate with a table full of hundreds of keys on keyrings

# Keys to the Waiting List

- Set up table just outside House Chambers
- Delivered the Keys with limited explanation
  - ▣ Invited legislators and staff back to the table
  - ▣ Person at the table to talk numbers and data
- Campaign from home
  - ▣ Call
  - ▣ Email
  - ▣ Fax
  - ▣ Mail Postcards



Postcard "Greetings OKLAHOMA from your Oklahoma constituent!"

# Opening the Discussion

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- From Keying the Capitol to invitation to talk about the issues
- Relationships built
- Training requested for all legislators
- Found buy-in from key Legislators or “Gatekeepers”
- Personal invitation to training

# Disability Training for State Legislators

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- What is a developmental disability
- What is an intellectual disability
- What it means to support families
- History of developmental disability services in Oklahoma
- ADA, Olmstead Decision, Homeward Bound Decision



# Waiting List Caucus

- Required all Member's vote reflect their commitment to the Waiting List
- Co-chair, Bipartisan
- Senators and Representatives
- Family Leaders from the DDS Act partners
- DD Agency leader with authority



Oklahoma Waiting List Caucus logo

# Outcomes of Waiting List Caucus

Oklahoma Gazette highlights the work of the DD Act Family Leaders' partnership with the State Legislature to find help for those on the DDS Waiting List  
RoseAnn Duplan, Oklahoma Disability Law Center, Wanda Felty, Center for Learning and Leadership./UCEDD, Erin Taylor, Oklahoma Developmental Disability Council

<https://www.okgazette.com/oklahoma/advocating-respite/Content?oid=3272957>



RoseAnn Duplan, Oklahoma Disability Law Center, Wanda Felty, Center for Learning and Leadership./UCEDD, Erin Taylor, Oklahoma Developmental Disability Council

# Outcomes of Waiting List Caucus

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- Most if not all legislators know about DD services and the Waiting List
- Creation of the first HCBS Waiver to help support people on the Waiting List (last created DD Waiver 1998)
- Largest one-time appropriation to work the Waiting List

# Lessons Learned

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- **Don't be good at the same thing**
- **Agree on the outcomes; negotiate the methods**
- **Bring one alone**
- **Have mentors outside the movement**
- **Don't dilute the advocacy with multiples issues**
- **Careful and temporary alliances with other groups**
- **Tend to one another**

# Contact Information

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**Wanda P. Felty**

Center for Learning and Leadership/UCEDD

Oklahoma LEND

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[www.ouhsc.edu/thecenter](http://www.ouhsc.edu/thecenter)



**Center for Learning and Leadership**

Oklahoma's University Center for Excellence in Developmental Disabilities (UCEDD)  
University of Oklahoma Health Sciences Center – College of Medicine