

# UCP PUBLIC POLICY

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Committee Chair & National Board of Trustees Member,  
Jeanne De Sa

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# WHAT WE DO AT UCP NATIONAL



# STRATEGIC DIRECTION

## **The Public Policy committee:**

- Representatives from the affiliate network
- Volunteers from across the United States
- UCP national board members with expertise in public policy

## **The charge of the committee:**

- Provide regular direction and guidance to staff
- Develop an initial policy platform reflecting organizational priorities and resources, the policy outlook, and affiliate insights
- Review and update UCP's public policy positions
- Develop a long-term strategy to enhance UCP's public policy activities

# PUBLICATIONS



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UCP National currently produces the following policy-related materials:

- Periodic comments on public policy issues with media
- Disability Policy Agenda (a joint annual publication produced with The Arc, ANCOR, NACDD, and AAIDD)
- Website resources about Congressional bills on UCP.Org
- Case for Inclusion report [TO BE TABLED in 2017]

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# VISIBILITY



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## National UCP activities

- Invites to UCP staff members to: White House, federal agency discussions and briefings, Capitol Hill events and briefings
- Presentation in policy-focused events and media focused on disability, health care, education and workforce (and others)
- Substantive engagement with policymakers and thought leaders in policy community (one-on-one or small group)

## Benefits of activities

- Enhanced visibility of issues important to UCP
- Greater influence for improving and advancing policies
- Opportunities for partnerships and ongoing relationships

## Example

- Karin Hitselberger, UCP Public Education Associate, serves on the National Youth Transition Advisory Board for Got Transition and also represents UCP with the National Youth Transitions Collaborative

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# LETTERS AND COMMENTS





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## Value of UCP brand for public policy

- Invitations to join disability groups in advocacy activities
- Opportunities to highlight issues important to affiliates and offer specific direction to federal regulatory agency and legislators
- Broader policy community views as expert resource and voice for issues related to Cerebral Palsy and disability more broadly

## Examples:

- Multiple opportunities to sign on to letters related to the ACA and other administration initiatives
- Joint comments to the FDA on the continued use electro-shock therapies
- An amicus brief in upcoming *Endrew v. Douglas County ESSA* SCOTUS case

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# EVENTS



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UCP co-produces public policy events throughout the year, as funding and opportunities arise:

- Disability Policy Seminar (a jointly sponsored annual conference in D.C. covering a variety of topics in I/DD policy and a Lobby Day)
- UCP also co-produced a convening with the National Council on Disabilities on Law Enforcement issues in December, 2016

# SOCIAL MEDIA



# SOCIAL MEDIA

UCP shares public policy publications, news stories, and resources (for example, blog posts about recently introduced bills in Congress) from the UCP website on social media with the public.

- Current Facebook Audience: 41,492
- Current Twitter Audience: 7,759

Opportunities to leverage this resource to a greater extent – including through partnerships with expert stakeholders

# COALITION-BUILDING



# COALITION BUILDING

**Disability-focused:** UCP and ANCOR both participate in many of the same coalitions focused on disability issues

## **Additional coalitions**

- Disease/condition-specific and patient-focused advocacy like: ITEM, HAB, Partners for Better Care, PIPC, and DRRC coalitions
- Opportunity to broaden our message and visibility around research, treatments, and equipment
- Recent letter sign-on process raises opportunities for more partnerships

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# CAPACITY





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# COMMITTEE CAPACITY

The Public Policy committee has representatives from the affiliate network, volunteers from across the U.S. and UCP national board members with expertise in public policy.

# PUBLIC POLICY AT UCP NATIONAL

## Current resources

- Ellie Collinson is National UCP's registered federal lobbyist
- Available for public policy activities the majority of her time, but also has responsibility for coordinating technology programs, managing grants (including PCORI), and oversees I&R and communications

## Environment and demands

- Chaotic and confusing policy environment at the federal level, risks and opportunities
- Generating lots of interest for activities, calls to action, policy education and updates, opportunities for engagement

**Approach** - Focus on leveraging partnerships and targeting efforts, while keeping eye on future ways to enhance policy role



## GR Staff, Roles, and Key Consultants



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### Other Key Consultants & Coalitions:

Alfonso Guida, Guide Consulting





## Preview of 2017 Work

- Block grant, per capita cap, and ACA repeal/replace proposals
- Workforce and adequate funding for services
- Enforcement of the ADA, IDEA, DD Act and other key legislation
- Interagency work and collaboration
- Oversight and investigation policies
- Provider stakeholder engagement





# ANCOR Amplifier and Action Alert system

[AMPLIFIER HOME](#)[SOS CAMPAIGN](#)[ISSUES](#)[RESOURCES](#)[ACTION CENTER](#)[ANCOR.ORG](#)

## Community Supports

People with Disabilities Want to Live, Work, and Play in their Communities, Just Like the Rest of Us! People with disabilities are valued members of our society, and deserve to be treated with dignity and respect, and have opportunities to participate fully in their communities.

[LEARN MORE ►](#)

## Take Action Now

Join the ANCOR Action Network by informing your elected officials about the following issues:

### **Speak Up Now: Tell Congress to Protect HCBS As Changes Begin**

Tell Congress to protect HCBS as it starts changing programs.



## Key Meetings: Leadership Summit, GR Retreat

- Leadership Summit **September 18-19, 2017**  
Dupont Circle Hotel, Washington, DC
- GR Retreat: **January 9-10, 2018**  
Hotel Monaco Baltimore, Baltimore, MD



# STRATEGIC DIRECTION

From the By-Laws:

*The Public Policy Committee shall be responsible for*

- (a) affecting social, governmental and political issues and concerns relevant to the member affiliates, people with disabilities, and their families,*
- (b) determining how UCP can anticipate and adjust to public policy trends in order to more effectively achieve its goals and fulfill its mission;*
- (c) recommending the formulation and adoption of basic policies, positions and advocacy activities concerning broad public policy issues;*
- (d) engaging, as appropriate, in legal advocacy;*
- (e) such other duties as assigned by the Board.*



# PROFESSIONAL COUNCIL PLAN

**Service #2: Public Policy primary responsibility lies with BOT Public Policy committee**

Outcome:

- UCP positively impacts disability policy, which continually and clearly furthers the organizational mission
- Supports a vibrant affiliate network
- Enhances opportunities for those living with disability and their families.



# PROFESSIONAL COUNCIL PLAN – GOAL A

**Policy Platform** - Develop and implement a Policy “Platform” which is inclusive of organizational mission, vision, values, as well as network policy priorities, and with Board guidance, which is dynamic and fluid to assure responsiveness to political and environmental fluctuations.

- *Define policy activity with a two-pronged approach- big and small “p”*
- *Consider an organizational policy around public policy (frequency of review, how changes determined, accountability related to staff, etc.) or Board Policy Committee Charter*
- *Ensure platform reflects wisdom of network and supports external stakeholder interests as feasible. **IN DEVELOPMENT***

**ANCOR** - Develop a plan/strategy to work with ANCOR to assure common terminology, non-duplication of efforts, routine staff communications, and “division” of labor. **IN DEVELOPMENT**

**Promotion** - Utilize the UCP communication tools to routinely promote policy activities, advocacy needs from network and external stakeholders. **TO BE DETERMINED IN CONJUNCTION WITH MEMBERSHIP**

## PROFESSIONAL COUNCIL PLAN – GOAL B

Overall goal - develop and utilize Strategic Partnerships to impact policy outcomes which positively enhance the landscape for the UCP network and those living with Cerebral Palsy and related disabilities and their families.

Execute ANCOR agreement. ***DONE 1/1/17***

Develop, foster, and take leadership role in relationships with stakeholder groups & coalitions, impacted by UCP mission (i.e. CPF, Nat'l parent groups). ***ONGOING***

Secure pro bono (i.e. via university research or marketing depts.) assessment of a viable “membership program” for approval and implementation. ***TO BE COORDINATED WITH MARKETING***

# THE POLICY PLATFORM

- Assess evolving policy landscape and opportunities for strategic engagement and advocacy
- Define our policy priorities with focus on issues of importance to affiliates
- Define the role UCP will have (lead, partner, monitor) and tactical approaches
- Serve as a resource for national staff in enhancing visibility, engaging with policy community, and participating in partnerships
- Synergies with UCP activities more broadly
- Resource for affiliates
- Guide pursuit of opportunities for UCP to regain capacity, through either grant funding or membership

# AFFILIATE ENGAGEMENT/ ALIGNMENT

## Next Steps:

- Discussions in Nashville
- Policy committee framework draft based
- Engagement of affiliates (questionnaire, other)
- Iteration on specific items with affiliate experts
- Identification and resolution of approaches for areas without alignment
- A Draft Document for Discussion
- A Board Ratification in December

# QUESTIONS?

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