

# YouthACT Transition Truths National Online Dialogue

# May 19, 2016 – May 22, 2016 Final Report





# **Table of Contents**

Introduction	3
Dialogue Key Words	2
Dialogue Participation Timeline	2
Outreach Efforts	
Dialogue Outreach Emails	
Initial Announcement Email 1 – 5/17/16	
Initial Announcement Email 2 – 5/17/16	
Dialogue Open Announcement Email 1 – 5/19/16	5
Dialogue Open Announcement Email 2 – 5/19/16	5
Dialogue Participation Reminder Email – 5/20/16	6
Dialogue Participation Reminder Email – 5/21/16	6
Last Day of Dialogue Reminder Email – 5/22/16	6
Participation Thank You Email – 5/23/16	6
Total Dialogue Outreach Emails	6
Dialogue Participation Summary	8
Campaign Summary	9
Visits during the Dialogue (5/19/16 – 5/22/16)	11
Map of Demographics of United States Visits	
Demographics of Visits	
Participation by Age Metrics	
Registration Metrics	
Infographics Depicting Popular Ideas Contributed by Dialogue Participants	
Top Ideas by Vote	
Most Active Ideas	
Trending Ideas	
Top 5 Overall Ideas	
Top Idea #1: Working together	
Top Idea #2: Vocational Rehabilitation	
Top Idea #3: Disability awareness and education	
Top Idea #4: Universal Design	
Top Idea #5: Jobs	
Top Ideas – Learning in High School and Beyond	
Top Idea #1: Working together	
Top Idea #2: Universal Design	
Top Idea #3: Pullout or Inclusion?	
Top Idea #4: Transition Counselor	
Top Idea #5: Life outside of the K-12 system	18
Top Ideas – Preparing for the Workforce	
Top Idea #1: Vocational Rehabilitation	
Top Idea #2: Jobs	10

Top Idea #3: Networking and Mentoring for Disabled People	19
Top Idea #4: Inclusive Apprenticeships	19
Top Idea #5: Higher Education and Career Paths	19
Top Ideas – Health & Healthcare Access	20
Top Idea #1: Medically Accurate Information	20
Top Idea #2: Transition to Adult Health Care	20
Top Idea #3: More Use of Email/Text by Medical Service Providers	20
Top Idea #4: Mental health integration	20
Top Idea #5: Access to medical care	21
Top Ideas – Advocacy and Self-Advocacy for Everyday Life	21
Top Idea #1: Learning about Self-Advocacy (before/during the transition age)	
Top Idea #2: Civil, Human Rights, Civil Liberty	21
Top Idea #3: A 9-step Process for Exceptional Self-Advocacy	21
Top Idea #4: Advocacy's Enemy: The 2 Big Roots of All Disability Issues	22
Top Idea #5: Your Right to Say "No"	23
Top Ideas – Voting and Community Engagement	<b>2</b> 3
Top Idea #1: Disability awareness and education	
Top Idea #2: Using the word disability	23
Top Idea #3: Volunteering as a graduation requirement?	24
Top Idea #4: I voted!	24
Top Idea #5: Participation in Community Activities	24
Top Ideas – Taking Care of Daily Life & Supports	24
Top Idea #1: An Anthem for the Exceptional	24
Top Idea #2: Roommate Location Service	25
Top Idea #3: Becoming independent	25
Top Idea #4: Addressing Barriers to Independence	25
Top Idea #5: Concerns about Individuals with Autism	25
Conclusion	26

# **Introduction**

The following report outlines the results of the ePolicyWorks' online dialogue, "YouthACT Transition Truths." Hosted by the U.S. Department of Labor's Office of Disability Employment Policy (ODEP) and the National Collaborative on Workforce and Disability for Youth (NCWD/Youth), this virtual event was held from Thursday, May 19, 2016 through Sunday, May 22, 2016. The online dialogue invited youth with disabilities and allies of the disability community to contribute to a virtual conversation in an effort to gather insight and ideas on strategies and supports that can help youth and young adults with disabilities and their peers become successful adults. Participants were encouraged to post new and innovative ideas and comment and vote on those posted by others.

To promote the sharing of ideas, the dialogue posed the following question to participants:

# What ideas do you have about what would help you and your peers become successful adults?

Ideas posted to the online dialogue were organized into the following six topics:

- 1. Learning in High School & Beyond
- 2. Preparing for the Workforce
- 3. Health & Healthcare Access
- 4. Advocacy and Self-Advocacy for Everyday Life
- 5. Voting and Community Engagement
- 6. Taking Care of Daily Life & Supports

Included in this report are the top posts contributed and voted on by participants. An archive of the complete dialogue is available for viewing at <a href="http://YouthIdeas.ePolicyWorks.org/">http://YouthIdeas.ePolicyWorks.org/</a>. The multitude of ideas gathered from this dialogue illustrate that collaboration and crowdsourcing with key stakeholders are imperative for the advancement and development of policies and best practices to support youth transition. Results of this online event will be used to help policymakers and people who work with youth to better understand what supports youth need to become successful adults.

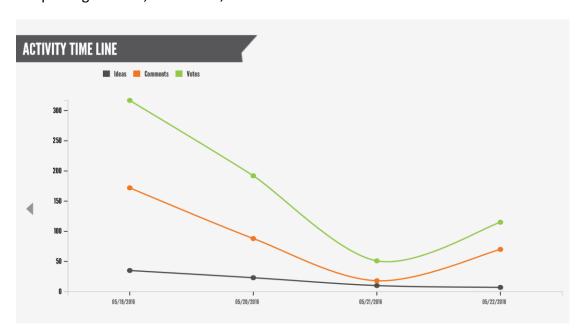
# **Dialogue Key Words**

The following is a word cloud containing the words most commonly used by participants throughout the dialogue. Main key words that illustrate the ideas discussed during the dialogue include: disability, health, school, youth, peers, job, help, life, care, work and need.



# **Dialogue Participation Timeline**

The following graph depicts the timeline of activity that occurred during the dialogue, including the posting of ideas, comments, and votes.



## **Outreach Efforts**

In order to engage a broad range of participants in the ePolicyWorks online dialogues, our team uses a multitude of strategic outreach efforts. At the start of every dialogue, initial outreach emails are sent to experts and key stakeholders relevant to the dialogue topic. In addition, emails are sent to the complete ePolicyWorks distribution list, which includes previous online dialogue invitees and ePolicyWorks Collaborative Workspace members. To focus the conversation for this specific dialogue, the ePolicyWorks team researched targeted organizations, including disability and youth advocacy organizations, and customized the correspondences to them.

Throughout the dialogue, the ePolicyWorks team sent follow-up reminder emails to ensure that everyone interested in participating in the online dialogue had the chance to do so before the dialogue closed. At the conclusion of the dialogue, a thank you email was sent to all participants with an invitation to stay tuned for future dialogues. Our email outreach strategy is critical to informing and shaping the conversation in every online dialogue, ensuring that the right people are brought to the table to contribute.

In addition to targeted email blasts, the ePolicyWorks team conducted outreach using social media through Twitter. This outreach tactic proved especially effective, as the dialogue was directed toward youth with disabilities, among whom social media use is quite popular. In the week leading up to the chat, four general announcement Tweets about the dialogue were posted. The day before the dialogue opened, ePolicyWorks sent direct tweets to the 45 prominent disability organizations and respected disability leaders listed below:

- @DisMentors National Disability Mentoring Coalition
- @DIS DPC Disability & Intersectionality Summit
- @DisVisibility Disability Visibility Project
- @HonTonyCoehlo Tony Coehlo
- @KesslerFdn Kessler Foundation
- @HabenGirma Haben Girma
- @LEDERICK LeDerick Horne
- @RealEconImpact National Disability Institute
- @ability2thrive Easter Seals Thrive
- @rootedinrights Rooted in Rights
- @diegomariscal 2Gether International
- @Diversability Diversability
- @Sblahov Sarah Blahovec
- @GimpJensen Jensen Caraballo

- @autselfadvocacy Autistic Self Advocacy Network
- @NYCDisabilities NYC Mayor's Office for People with Disabilities
- @MgmAUCD Michael Gamel-McCormick
- @ReeveFoundation Reeve Foundation
- @Queerability Queerability
- @ourcareeraccess CareerACCESS
- @NationalAPSE Association of People Supporting Employment
- @thinkingautism Thinking Person's Guide to Autism
- @FCMichigan Friendship Circle
- @RudermanFdn Ruderman Foundation
- @Easter Seals Easter Seals
- @ESCrossroads Easter Crossroads
- @RampYourVoice Ramp Your Voice
- @WID org World Institute on Disability
- @BeyondTheLabel Beyond the Label
- @NACDD National Council On Developmental Disabilities
- @Yodisabledproud YO! Disabled and Proud
- @LeadOnUpdate LeadOn Update
- @Respect\_Ability RespectAbility
- @ aaidd American Association on Intellectual and Developmental Disabilities
- @TheArcUS The Arc
- @UCPnational United Cerebral Palsy
- @NOD ItsAbility National Organization on Disability
- @IntDisability Judy Heumann
- @GreggBeratan Gregg Beratan
- @NDRNadvocates National Disability Rights Network
- @chaifeldblum EEOC Commissioner Chai Feldbllum
- @AUCDnews Association of University Centers on Disabilities
- @AndyAUCD Andy Imparato
- @LEADCtr LEAD Center
- @AFB1921 American Federation of the Blind

In addition to the above noted efforts, eight original tweets were posted throughout the course of the four day event, with 20 retweets, and @ePolicyWorks re-tweeted seven announcements from other accounts about the dialogue. Our targeted social media outreach contributed to a significant increase of dialogue promotion on social media and by directing interested people

and organizations to register for the dialogue. In total, twenty-two percent of new visitors to the dialogue came from social media.

# **Dialogue Outreach Emails**

#### Initial Announcement Email 1 – 5/17/16

This email announcing the start of the dialogue and personally inviting participants was sent to previous dialogue participants.

- Emails Delivered 7,551
- Emails Opened 1,761
- Total number of clicks on links in email (excluding multiple clicks of the same link) 427

#### Initial Announcement Email 2 – 5/17/16

This email announcing the start of the dialogue and personally inviting participants was sent to disability bloggers and disability and youth advocacy organizations.

- Emails Delivered 113
- Emails Opened 46
- Total number of clicks on links in email (excluding multiple clicks of the same link) 27

## Dialogue Open Announcement Email 1 – 5/19/16

This email announcing the start of the dialogue was sent to people who were already registered to participate.

- Emails Delivered 316
- Emails Opened 154
- Total number of clicks on links in email (excluding multiple clicks of the same link) 67

### Dialogue Open Announcement Email 2 - 5/19/16

This email announcing the start of the dialogue was sent to ePolicyWorks contacts who were not yet registered to participate.

- Emails Delivered 1,407
- Emails Opened 355
- Total number of clicks on links in email (excluding multiple clicks of the same link) 53

## Dialogue Participation Reminder Email - 5/20/16

This email was sent to all current dialogue registrants to encourage them to return to the dialogue to contribute more ideas, votes and comments.

- Emails Delivered 189
- Emails Opened 80
- Total number of clicks on links in email (excluding multiple clicks of the same link) 21

# **Dialogue Participation Reminder Email – 5/21/16**

This email was sent to disability bloggers and disability and youth advocacy organizations to encourage dialogue participation and spreading the word.

- Emails Delivered 114
- Emails Opened 35
- Total number of clicks on links in email (excluding multiple clicks of the same link) 6

## Last Day of Dialogue Reminder Email - 5/22/16

This email was sent to dialogue registrants to encourage participation before the dialogue closed.

- Emails Delivered 442
- Emails Opened 180
- Total number of clicks on links in email (excluding multiple clicks of the same link) 70

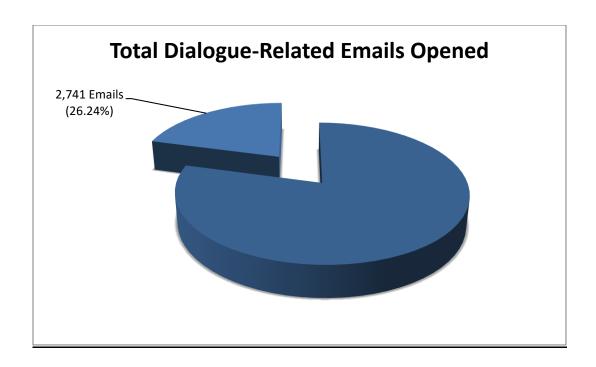
# Participation Thank You Email – 5/23/16

This email was sent to all dialogue registrants to thank them for their contributions to the dialogue.

- Emails Delivered 315
- Emails Opened 130
- Total number of clicks on links in email (excluding multiple clicks of the same link) 38

# **Total Dialogue Outreach Emails**

- Email Blasts 8
- Emails Delivered 10,447
- Emails Opened 2,741 (26.24% open rate)
- Total number of clicks on links in emails (excluding multiple clicks of the same link) 709

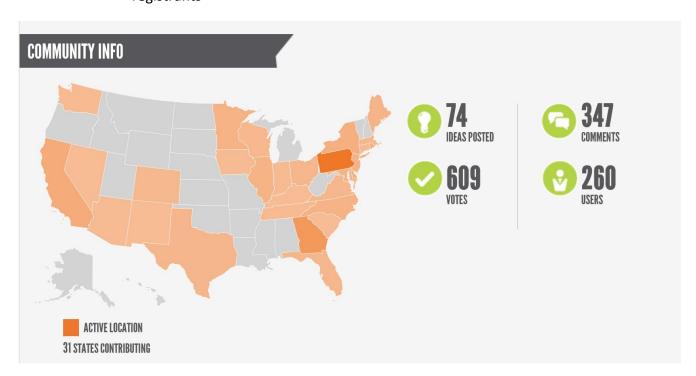


With a combined 2,741 dialogue-related emails opened, ePolicyWorks had a strong 26.24% open rate, directly impacting the success of the online dialogue. Links included in the emails were clicked a total of 709 times, leading recipients to register and get involved in the dialogue.

Note: The following section outlines the key metrics from the online dialogue and provides a snapshot of the participation results.

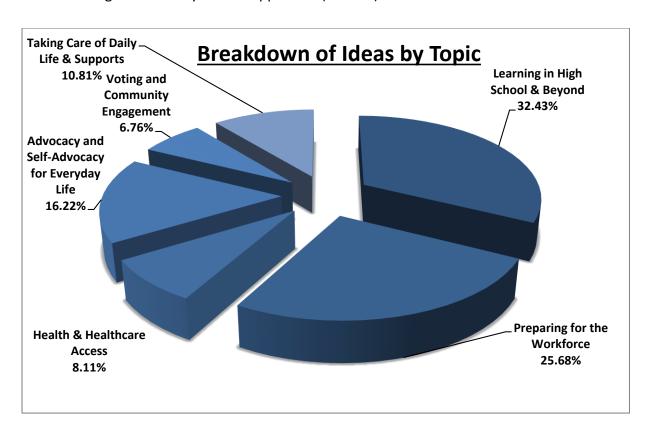
# **Dialogue Participation Summary**

- Dialogue opened on Thursday, May 19, 2016 at 8:00 am ET
- Dialogue closed on Sunday, May 22, 2016 at 11:59 pm ET
- Total Ideas: 74
- Total Comments: 347
- Total Votes: 609
- Unique Visitors: 760
- Total Registrants: 453 (59.6% of unique visitors)
  - Completed Registration: 429 (94.7% of total registrants)
  - Active Registrants (submitted ideas, voted or commented): 116 (27.04% of total registrants

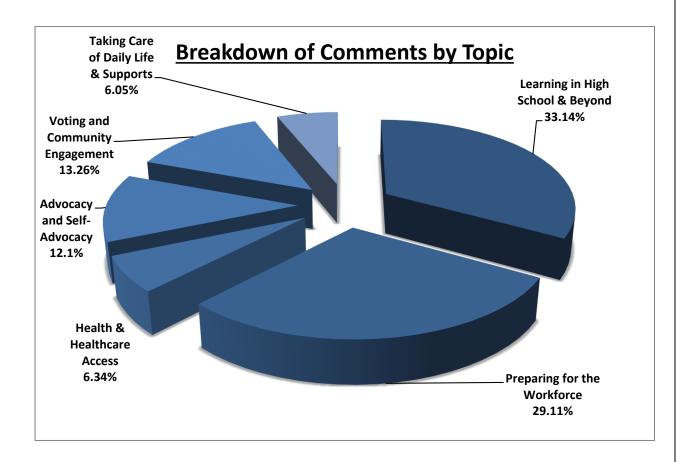


# **Campaign Summary**

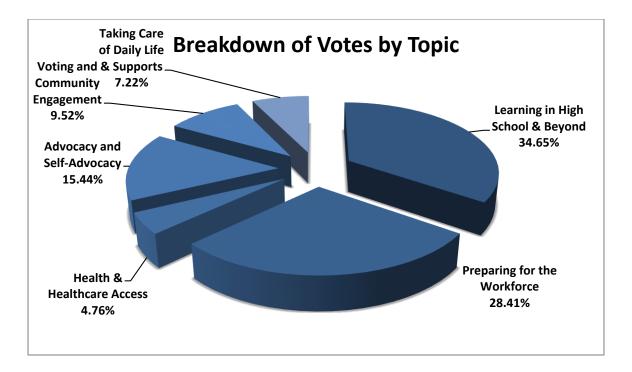
- Total number of ideas: 74
  - o Learning in High School & Beyond: 24 (32.43%)
  - Preparing for the Workforce: 19 (25.68%)
  - Health & Healthcare Access: 6 (8.11%)
  - Advocacy and Self-Advocacy for Everyday Life: 12 (16.22%)
  - Voting and Community Engagement: 5 (6.76%)
  - Taking Care of Daily Life & Supports: 8 (10.81%)



- Total number of comments: 347
  - Learning in High School & Beyond: 115 (33.14%)
  - o Preparing for the Workforce: 101 (29.11%)
  - Health & Healthcare Access: 22 (6.34%)
  - Advocacy and Self-Advocacy for Everyday Life: 42 (12.10%)
  - Voting and Community Engagement: 46 (13.26%)
  - o Taking Care of Daily Life & Supports: 21 (6.05%)



- Total number of votes: 609
  - Learning in High School & Beyond: 211 (34.65%)
  - Preparing for the Workforce: 173 (28.41%)
  - Health & Healthcare Access: 29 (4.76%)
  - Advocacy and Self-Advocacy for Everyday Life: 94 (15.44%)
  - Voting and Community Engagement: 58 (9.52%)
     Taking Care of Daily Life & Supports: 44 (7.22%)



# **Visits during the Dialogue (5/19/16 - 5/22/16)**

• Total visits: 1,156

• Unique visitors: 760

• Total page views: 9,447

• Average pages per visit: 8.17

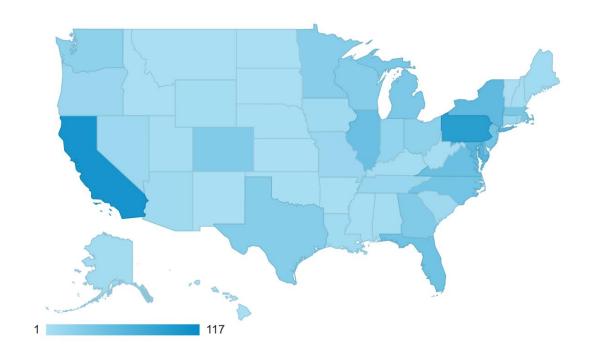
Average visit duration: 10:18

• Returning visitors: 49.4%

• Bounce rate (percentage of participants who leave after viewing the first page of the

dialogue): 39.79%

# **Map of Demographics of United States Visits**



# **Demographics of Visits**

State	Visits	
District of Columbia	117	
California	106	
Pennsylvania	92	
Maryland	57	
New York	53	
Delaware	46	
Illinois	46	
Virginia	45	
Florida	41	
North Carolina	39	
New Jersey	38	
Massachusetts	35	
Michigan	33	
Georgia	30	
Colorado	29	
Texas	27	
Wisconsin	27	

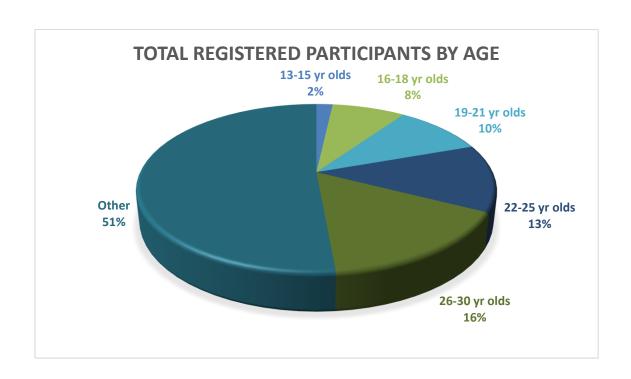
State	Visits	
Minnesota	25	
Ohio	21	
Indiana	18	
Tennessee	14	
Connecticut	12	
Missouri	12	
Oregon	12	
Nevada	11	
Rhode Island	11	
South Carolina	9	
Arizona	8	
Iowa	8	
Louisiana	7	
Maine	7	
Alaska	6	
Alabama	5	
Kentucky	5	

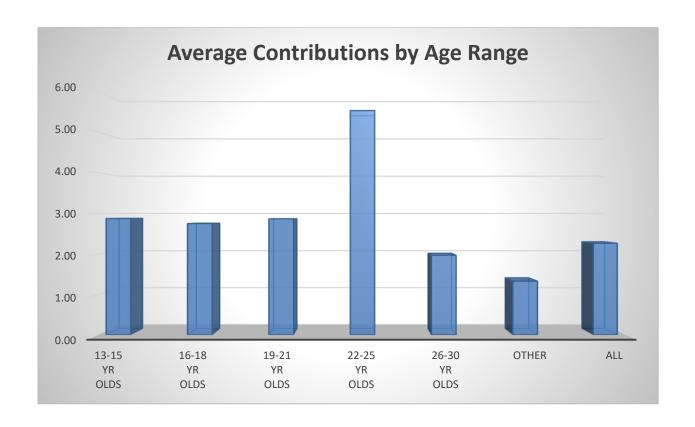
State	Visits	
Wyoming	5	
Mississippi	4	
New Hampshire	4	
Utah	4	
West Virginia	4	
Arkansas	3	
Nebraska	3	
Oklahoma	3	
Idaho	2	
New Mexico	2	
Hawaii	1	
Kansas	1	
Montana	1	
North Dakota	1	
South Dakota	1	

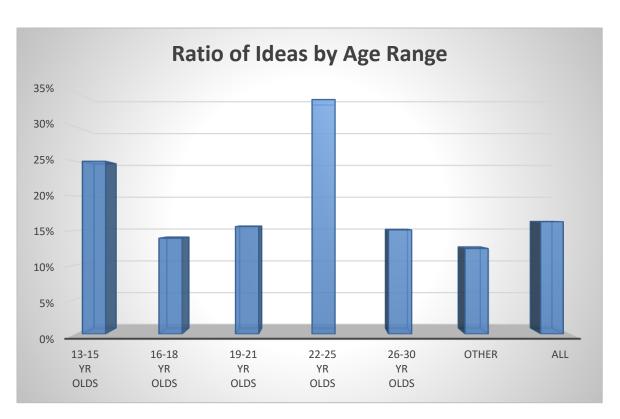
# **Participation by Age Metrics**

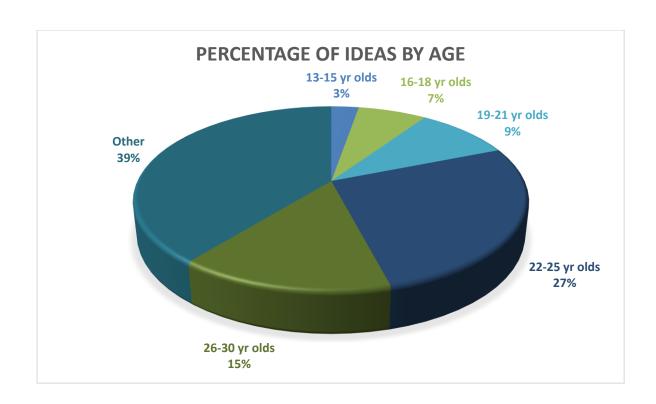
As part of the registration process, participants were asked to identify their age group (13-15, 16-18, 19-21, 22-25, 26-30 or other). The following table and graphs describe the breakdown of participation in the dialogue by age groups. It should be noted that though there were less participants in the age ranges between 13 to 30 years old, they participated at a much higher rate, contributing more ideas, comments and votes, than those who identified themselves as "other." In particular, the age range from 13-15% had the fewest registered participants, but the second highest participation rate.

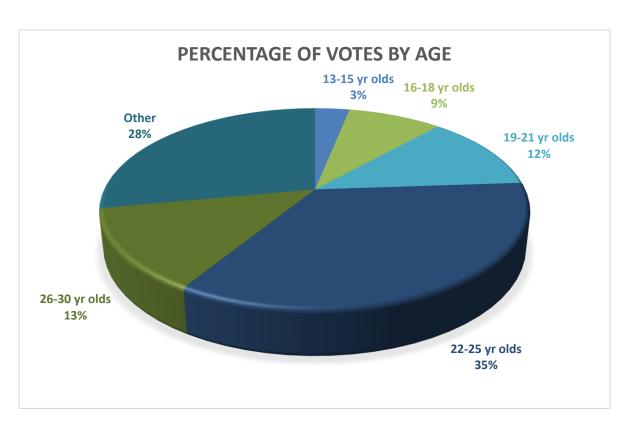
Age	Total Ideas	Total Votes	Total Comments	Total Registered Participants	Participation Rates for Ideas
13-15 yr. olds	2	19	2	8	25%
16-18 yr. olds	5	52	42	36	14%
19-21 yr. olds	7	75	47	45	16%
22-25 yr. olds	20	213	93	59	34%
26-30 yr. olds	11	81	52	73	15%
<u>Other</u>	<u>29</u>	<u>171</u>	<u>111</u>	<u>234</u>	<u>12%</u>
Total	74	611	347	455	16%

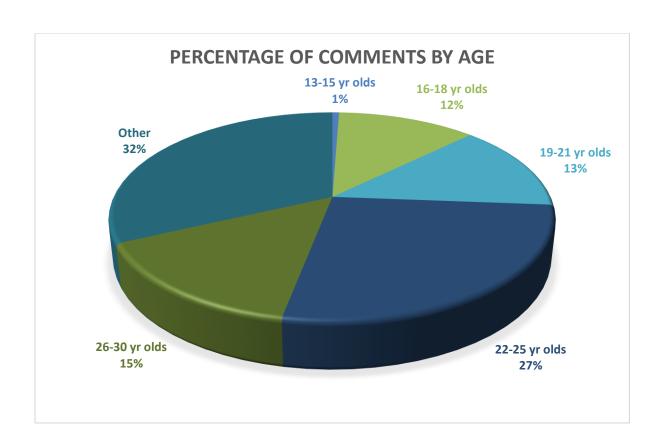












## **Registration Metrics**

Total registrants: 453

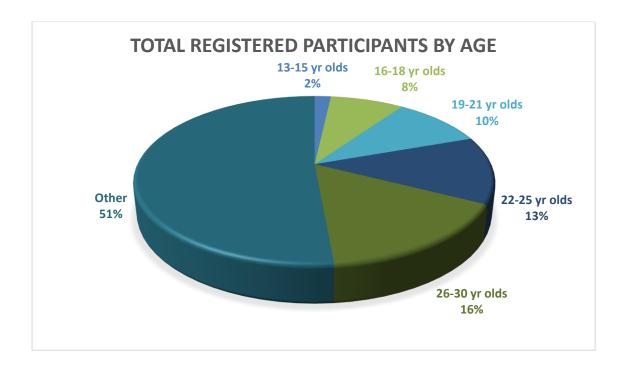
Total number of registrants that completed the registration process: 429

As part of the dialogue registration process, registrants were asked to answer a series of questions, including:

- 1. Please select your age range. Choose one.
- 2. If you wish to share what type of disability you have, please select your disability or disabilities from the list below. Feel free to check multiple boxes.
- 3. Please check the type(s) of school or educational programs you are currently participating in or have completed. Feel free to check multiple boxes.
- 4. Please check the type(s) of work experience you are currently participating in or have done in the past. Feel free to check multiple boxes.

Listed below is a breakdown of registration responses:

1. Please select your age range. Choose one. (see previous section)



# 2. If you wish to share what type of disability you have, please select your disability or disabilities from the list below. Feel free to check multiple boxes.

Autism: 60 (9%)Deafness: 11 (2%)

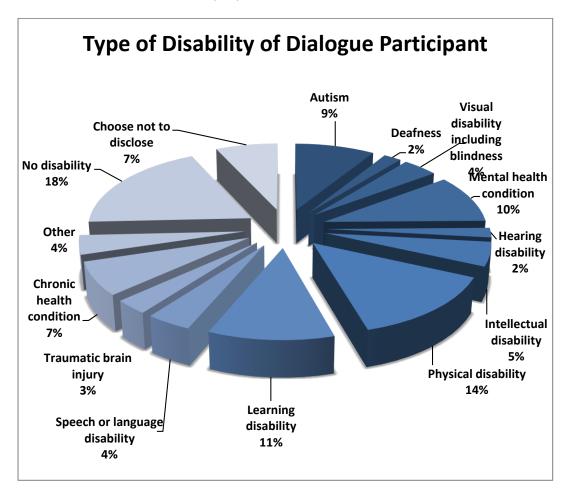
• Visual disability including blindness: 26 (4%)

Mental health condition: 66 (10%)

Hearing disability: 14 (2%)
Intellectual disability: 36 (5%)
Physical disability: 93 (14%)
Learning disability: 73 (11%)
Speech or language: 26 (4%)
Traumatic brain injury: 22 (3%)

Chronic health condition: 44 (7%)Other: 27 (4%)

Choose not to disclose 46 (7%)



Please check the type(s) of school or educational programs you are currently participating in or have completed. Feel free to check multiple boxes.

Middle School/Junior High: 115 (15%)

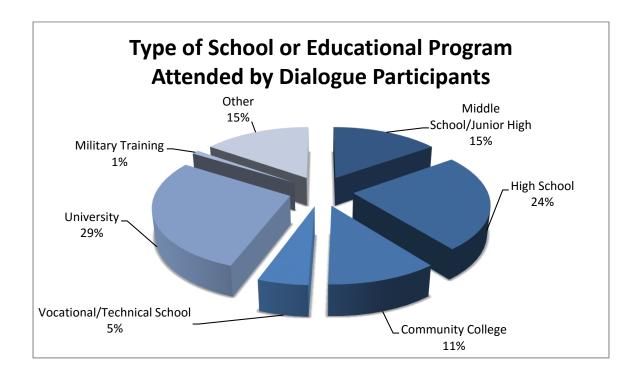
• High School: 181 (24%)

• Community College: 81 (11%)

• Vocational/Technical School: 41 (5%)

University: 210 (28%)Military Training: 10 (1%)

• Other: 115 (15%)

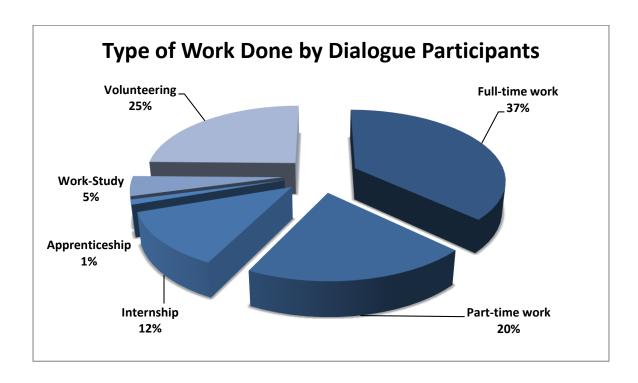


# 3. Please check the type(s) of work experience you are currently participating in or have done in the past. Feel free to check multiple boxes.

Full-time work: 248 (33%)Part-time work: 137 (18%)

Internship: 80 (11%)
Apprenticeship: 10 (1%)
Work-Study: 33 (4%)
Volunteering: 164 (22%)

• Other: 87 (11%)



# <u>Infographics Depicting Popular Ideas Contributed by Dialogue Participants</u>

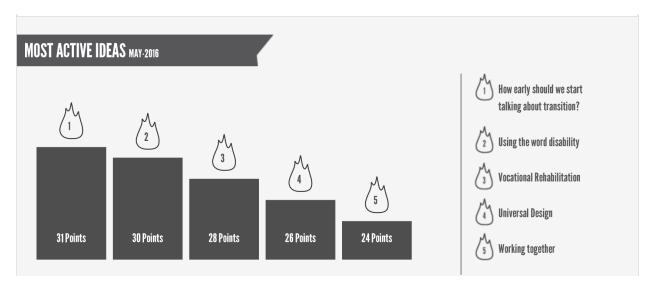
# **Top Ideas by Vote**

The following chart depicts top ideas submitted by participants based on the number of votes the ideas received from other participants.



#### **Most Active Ideas**

The following chart depicts the ideas submitted by participants that were the most commented on and voted on by other participants.



# **Trending Ideas**

The following chart depicts the ideas submitted by participants that were trending based on interactions from other participants.



Note: The ideas listed in the following sections include minor typographical corrections, which have in no way impacted the substance or the intention of the revised posts.

# **Top 5 Overall Ideas**

#### Top Idea #1: Working together

16 Up Votes | 0 Down Votes | 16 Net Votes

As a vocational rehabilitation counselor who works with my local schools and attends IEP meetings, I believe that it is so important for case managers and HS guidance counselors to have ongoing dialog with the students and parents to help GUIDE them on the realities of life after high school so that they can make informed choices.

#### Top Idea #2: Vocational Rehabilitation

14 Up Votes | 0 Down Votes | 14 Net Votes

Vocational Rehabilitation agencies vary in each state. With new legislation, they are required to begin services with individuals with disabilities as early as 14 years old. At one VR in Georgia, they have implemented Job Club which allows a VR Counselor to come into the high schools in that county. That VR Counselor is responsible for introducing ideas such as budgeting, interviewing skills, do's and don'ts in the work place, resume writing, how to maintain a job, how to decide what the career goal should be, etc. Excellent resource that's available.

#### Top Idea #3: Disability awareness and education

13 Up Votes | 0 Down Votes | 13 Net Votes

The public needs to have a better understanding of disabilities. In order for our culture to become more accepting and less afraid of people with disabilities, they need to be better educated. It would be nice if there was an organization whose sole purpose was to enlighten businesses and provide support to them in becoming truly integrated. It would also be nice if the government gave some sort of incentive for businesses to take part in such training.

#### Top Idea #4: Universal Design

14 Up Votes | 1 Down Votes | 13 Net Votes

As a coordinator for disability services in higher education, I think it is important to mention the idea of universal design. If curriculums and classwork were designed with universality in mind, the need for disability services would subside. Students would not need to self-identify as having a disability because the course work would be designed to be accessible to all types of learners. There is a way to present information in a variety of formats or media so that everyone can access it. As it stands in this country, universities and colleges require students to report that they have a disability in order to receive the accommodations to give them equal access. Many students do not report because of the stigma, but also because of the process. The process usually involves providing documentation, scheduling appointments, etc., which can be a barrier in itself in certain instances. If a program were truly universal, there would be no need for special accommodations.

#### Top Idea #5: Jobs

13 Up Votes | 0 Down Votes | 13 Net Votes

We need to provide more job opportunities for people with disabilities.

## <u>Top Ideas – Learning in High School and Beyond</u>

## Top Idea #1: Working together

16 Up Votes | 0 Down Votes | 16 Net Votes

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#### Top Idea #2: Universal Design

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As a coordinator for disability services in higher education, I think it is important to mention the idea of universal design. If curriculums and classwork were designed with universality in mind, the need for disability services would subside. Students would not need to self-identify as having a disability because the course work would be designed to be accessible to all types of learners. There is a way to present information in a variety of formats or media so that everyone can access it. As it stands in this country, universities and colleges require students to report that they have a disability in order to receive the accommodations to give them equal access. Many students do not report because of the stigma, but also because of the process. The process usually involves providing documentation, scheduling appointments, etc. which can be a barrier in itself in certain instances. If a program were truly universal, there would be no need for special accommodations.

#### Top Idea #3: Pullout or Inclusion?

10 Up Votes | 0 Down Votes | 10 Net Votes

Once a student leaves the general education classroom what will he/she lose or gain? Are they gaining speech or reading therapy and losing important time in say, math or science? Are they being taken out of gym or music class? These subjects are just as important to some students. What does the student gain by staying in the general education class? Will the student be ridiculed by his/her peers for leaving the classroom to attend therapy? Or will they be ridiculed in the classroom for having someone (a therapist) enter the general education classroom and work with a particular student? Is it better to work with students in a group so no one feels left out? This could then impact how well an individual does in therapy. What are some of the pros and cons for each method?

#### **Top Idea #4: Transition Counselor**

10 Up Votes | 0 Down Votes | 10 Net Votes

I think each high school should have a transition counselor(s) similar to the guidance counselors already in most high schools. They would be full-time, available at the school, and aware of both federal, state and local programs. They would be responsible for attending IEP meetings for the students and be a resource for applying for programs (federal, state, and local) as students enter transition age. They could help parents/guardians/students with important information given through what I've found to be very informal and often incomplete means (i.e. word of mouth or self-directed attempts to get information through multiple independent agencies). They could help bridge the gaps between vocational rehab, postsecondary programs, day programs, residential programs, home care, etc. Special needs students need just as much (if not more) help with post high school planning. I think having a position like this would be helpful to not just to parents/students, but the teachers who are often left trying to fill this role themselves in the absence of dedicated, full-time personnel.

#### Top Idea #5: Life outside of the K-12 system

10 Up Votes | 1 Down Votes | 9 Net Votes

Transition planning is critical, but often does not include organizational representatives who can continue to support a youth after K-12. When the re-authorization of I.D.E.A. begins to move forward I would like to see language in it that includes that community based organizations, such as Centers for Independent Living, must be invited to attend to support the youth and family throughout their transition out of K-12. This would allow a youth and family to meet with and get to know an adult role model with a disability, who ideally could be a mentor and resource to services and programs after high school.

# <u>Top Ideas – Preparing for the Workforce</u>

#### Top Idea #1: Vocational Rehabilitation

14 Up Votes | 0 Down Votes | 14 Net Votes

Vocational Rehabilitation agencies vary in each state. With new legislation, they are required to begin services with individuals with disabilities as early as 14 years old. At one VR in Georgia, they have implemented Job Club which allows a VR Counselor to come into the high schools in that county. That VR Counselor is responsible for introducing ideas such as budgeting, interviewing skills, do's and don'ts

in the work place, resume writing, how to maintain a job, how to decide what the career goal should be, etc. Excellent resource that's available.

#### Top Idea #2: Jobs

13 Up Votes | 0 Down Votes | 13 Net Votes

We need to provide more job opportunities for people with disabilities.

#### **Top Idea #3: Networking and Mentoring for Disabled People**

12 Up Votes | 0 Down Votes | 12 Net Votes

There should be more networking events exclusively designed for people with disabilities and disability employers. There also should be a mentorship program where people with disabilities can get advice from a professional.

#### **Top Idea #4: Inclusive Apprenticeships**

9 Up Votes | 0 Down Votes | 9 Net Votes

Apprenticeship programs are jobs that youth with disabilities could enroll in to earn money while developing their skills in a field of interest to them. Programs typically last a few years, and apprentices who complete them earn an average starting salary of \$50,000 a year. Historically, there have been many programs in fields like construction and manufacturing, but recently there has been a lot of growth in industries like healthcare and information technology. Apprenticeship programs are a great opportunity, but many youth with disabilities do not know they exist. Schools should educate transitioning youth about apprenticeships as an alternative to other expensive forms of postsecondary education. Also, employers who sponsor apprenticeships need to connect with the workforce system, VR, schools and community colleges, and other recruitment sources to engage youth with disabilities. Sponsors also need to make sure their program entry standards are not overly restrictive and could support a pre-apprenticeship program to help interested candidates meet the qualifications for the actual apprenticeship. Sponsors should think about how to use Universal Design for Learning (UDL) to make their programs accessible and should also be prepared to provide accommodations. I am a young person with a disability and know of some of my peers with disabilities who would greatly benefit from apprenticeships!

#### **Top Idea #5: Higher Education and Career Paths**

8 Up Votes | 0 Down Votes | 8 Net Votes

I am fairly new to this field, but I've found that many youth and adults with disabilities are either directed to jobs focusing on very menial tasks (cleaning, washing dishes, etc.) or employed in sheltered

workshops. While I believe that this is an acceptable option for some individuals, I think that there needs to be more focus early on for students to develop a career path (if deemed appropriate and realistic) and resources to assist them to access a higher education, and eventually a career that challenges them but is also fulfilling long term.

# Top Ideas - Health & Healthcare Access

#### Top Idea #1: Medically Accurate Information

7 Up Votes | 1 Down Votes | 6 Net Votes

What can we do as a community to promote medically accurate healthcare information so that people with all different disabilities are getting informed and educated information? I hear a lot of myths about people with disabilities not being interested in health, reproduction, sexuality, etc. - and that is why the information is not being provided or promoted.

#### Top Idea #2: Transition to Adult Health Care

4 Up Votes | 0 Down Votes | 4 Net Votes

Make up lists of 1. medical conditions 2. medications 3. hospitalizations/surgeries 4. treating doctors and bring them to each visit.

#### Top Idea #3: More Use of Email/Text by Medical Service Providers

4 Up Votes | 0 Down Votes | 4 Net Votes

It would be great if all medical/mental health service providers could make better use of text and email as a means of contact and appointment making. Talking on the telephone with strangers and navigating complicated voice mail systems make access to services difficult and impossible for many. Just the thought of going through that will cause them to put off needed medical attention.

#### Top Idea #4: Mental health integration

4 Up Votes | 0 Down Votes | 4 Net Votes

My neurologists never asked me how I'm emotionally coping with my epilepsy and the challenges it faces in daily life as I'm growing up. My feelings about my seizures effected my willingness to comply with prescriptions. We need doctors more attuned to the emotional impact of disabilities and an integration of mental health services.

#### Top Idea #5: Access to medical care

2 Up Votes | 0 Down Votes | 2 Net Votes

Find out if the doctor's office, exam tables, and diagnostic equipment are physically accessible before you make an appointment. If there is another mode communication needed (e.g. sign language) find out when (not if as they are required) interpreters are available. Make sure the doctors understand your disability in addition to any illness being treated.

# <u>Top Ideas – Advocacy and Self-Advocacy for Everyday Life</u>

#### Top Idea #1: Learning about Self-Advocacy (before/during the transition age)

9 Up Votes | 0 Down Votes | 9 Net Votes

I am a youth that struggled self-advocacy. I would always let my mother advocate for me, and since she was so good at advocating I did not see the point in me even trying. When I started in high school I realized I needed to fight for my services otherwise they might not be fulfilled. I wish there was a program/video/book that helped middle schoolers, high school and beyond, to learn about self-advocacy. This could be for school, health-care, and for employment. If there is what is it?

### Top Idea #2: Civil, Human Rights, Civil Liberty

8 Up Votes | 0 Down Votes | 8 Net Votes

Discrimination, harassment, bullying in our schools from teachers to our children and parents. Also, in the courts. They are not following the laws i.e. ADA, 504 plan, IDEA, FAPE, etc. The No Fear Act. & so on. Thx

#### Top Idea #3: A 9-step Process for Exceptional Self-Advocacy

7 Up Votes | 0 Down Votes | 7 Net Votes

The whole purpose of self-advocacy is to stand up for yourself and take ownership of everything in your life under any circumstance. A philosophy that I recommend for self-advocates of any background, age, etc. is to consistently take inventory of everything that happens in daily life and to dig deep. For example, if a man with Asperger's Syndrome has trouble with relationships, he could conduct some research using a variety of websites; some of which can be found on social media. He bases his self-support in his clear beliefs and accounts for all details in order to know and to get what he desires in attempts to resolve his predicament and to authentically enjoy his life. This constant, detail-oriented, and honest self-assessment is essential and the person with a disability must eventually acquire the ability to do it all himself. This often requires a bit of supported decision making, perhaps in the simple

form of basic and supportive family conversation. Although, bear in mind that, for any self-advocate, too much support is just as bad on the long-term as too little support. Below is a process that works for virtually any self-advocate: 1. Identify personal and professional life topics to examine; 2. Get a truthful and complete understanding where s/he stands in specific regards within those topics; 3. Identify as many supports as possible and sort out which ones work best for him/her through experimentation of those resources. Also, do so without initial external input (someone else's voice can negatively influence personal judgment during an assessment); 4. Commit to making ALL decisions that will impact his/her life while accordingly using sorted supports while keeping best interest in mind, no matter what!; 5. Take direct control over as much as possible in a given matter and accept what is beyond that control; 6. Set SMART (acronym) goals that get the precise results the self-advocate wants, but do not expect immediate results. Instead, think of it as a delicate timeline that runs at a particular pace; 7. Courageously and diligently work towards those goals and measure progress however possible; 8. Be kind to and honest with him/herself, no matter what others do to, with, or for him/her. 8. Understand that the entire process is an amazing, unique journey with obstacles and wrong turns. 9. Repeat this process or devise a similar process that works with equal efficiency. The ultimate goals for a selfadvocate, as well as anyone else, are real independence, purpose, and prosperity in his/her life. Everyone needs support and everyone must be able to support him/herself. With a process like this, a self-advocate cannot truly go wrong. Upon completion of such a process, a self-advocate can advocate for him/herself and for others at any time in any situation. Finally, everybody has a voice to lend and the collective voices of self-advocates build and maintain communities that have real integrity.

# Top Idea #4: Advocacy's Enemy: The 2 Big Roots of All Disability Issues

6 Up Votes | 0 Down Votes | 6 Net Votes

Ignorance and lack of accountability are ultimately the two major roots of negative influences of any kind in the educational system and the workforce alike. If you think about it, any disability-related issue stems from these two all-important and all-neglectful things. What one person does not understand comes back to victimize (sometimes intentionally, sometimes not) the student or his/her family in some manner. Likewise, what one person understands, but fails to do (or not do) in the right instant has similarly dire consequences. The mistakes range from failing to reply to emails to refusing to file charges against bullies. Although, for the latter, sometimes filing charges is not always the most appropriate solution. I said this several times already and I will say it again, ACCOUNTABILITY IS A MUST-HAVE FOR EVERYONE!!! A school or community is only as promising as anybody desires when everyone involved in it commits to excellence, service, and integrity; when all parties give it their all; when people do more than just the bare minimum of their jobs and responsibilities. We all have human rights and anything less than full support can certainly come across as unacceptable and in need of improvement, as it should come across. Do not just act, act in accordance with core virtues, missions, objectives, and sensitivity to context and situation. If everybody adopted this attitude; if everybody played the role as an advocate for at least one issue or subject, disability issues, like any other issues, would occur much less frequently and EVERYBODY would benefit from those collective efforts.

## Top Idea #5: Your Right to Say "No"

6 Up Votes | 0 Down Votes | 6 Net Votes

You have a right to say "No" to any clinician who you believe is not looking out for your best interest. After over a decade in personal self-advocacy, I have come across a number of doctors who have used unethical practices to coerce me to comply with their regime. In those cases, I refused to accept this doctor's, this someone else's prescriptions. It took me years of trusting every doctor because I had no better choice, and taking every pill handed to me, and the pill to counter the previous pills side effects, and more, in order to find the prescriptions and dosage that kept me stable and healthy. All was good until I moved to another city, in a different state. Unbeknownst to me, my medical care had nothing to do what was best for me. Instead, I was subjected to the community health clinic's "preferred formulas." My doctor had no agency to do what was right. Instead of being straightforward, I found out after six months that the truth was that if I wanted to get the help that I needed, then I needed to find a doctor who had the right to do what was right. Living with a psychiatric disability often means that your life is often in the hands of clinicians. Your doctor has power over your life. In my life, I came to the point where I realized that I needed to own my disability. I was no longer someone to slingshot. I was responsible for my care. At the same time, I need help. I need a doctor's insight, compliance, and concern for my wellbeing. At the very least, I need my prescriptions filled so that I can work on becoming independent for another month. I need that assurance, that peace of mind. Who doesn't? Thus, I believe that helping individuals set healthy boundaries for themselves can be empowering. A peer mentor suggested something to me, before stepping into their doctor's office, have what you want to say and your evidence written down in your own words. Hand that paper to your doctor and have it recorded in your file. Part of saying "No" is framing your "Yes" needs. By the way, the second part here is that "Yes," it makes a huge difference to have a peer support. Being disabled may be chronic, but every day we can become more abled. Thank you.

# **Top Ideas – Voting and Community Engagement**

#### Top Idea #1: Disability awareness and education

13 Up Votes | 0 Down Votes | 13 Net Votes

The public needs to have a better understanding of disabilities. In order for our culture to become more accepting and less afraid of people with disabilities, they need to be better educated. It would be nice if there was an organization whose sole purpose was to enlighten businesses and provide support to them in becoming truly integrated. It would also be nice if the government gave some sort of incentive for businesses to take part in such training.

#### Top Idea #2: Using the word disability

8 Up Votes | 0 Down Votes | 8 Net Votes

I feel like it's time to remove the word disability someone who disability can still live a normal life and get a job how would you feel if someone called you disability?? Think before you speak we are humans too describing someone as disability can really hurt someone feelings

#### Top Idea #3: Volunteering as a graduation requirement?

7 Up Votes | 0 Down Votes | 7 Net Votes

Some high schools require community service hours as a requirement for high school graduation. Do you think this should be a requirement?

#### Top Idea #4: I voted!

5 Up Votes | 0 Down Votes | 5 Net Votes

I'm 21. When I was 18, it was time to vote for Obama and Romney. I don't talk and I use a wheelchair. My mom spent several months talking to me about the candidates. We practiced voting by me slapping her right or left hand for the candidate I liked. She would switch hands to trick me (like Obama was right hand sometimes, and left hand sometimes). When she saw that I consistently chose the same candidate every time, she felt like I was ready to prove to the polling place that I was competent to vote. I rolled in - they were nervous about me voting but my mom assured them that I was ready - and I voted! It was awesome. It was my right and I exercised it! Now I get to do it again in November.

#### **Top Idea #5: Participation in Community Activities**

2 Up Votes | 0 Down Votes | 2 Net Votes

Students with disabilities should be active in activities just like peers. Even "special needs" activities recognize the importance of having peer buddies like Special Olympics, Miracle League, and Challenger Little League

# **Top Ideas – Taking Care of Daily Life & Supports**

#### Top Idea #1: An Anthem for the Exceptional

7 Up Votes | 0 Down Votes | 7 Net Votes

"Different ability, not disability"; "Look at the able, not the label"; "Keep telling me what I cannot do; It'll only make it more interesting when I accomplish it." These constitute three of many power statements as pillars for anthems that anybody enduring great challenges can express to show their real strength. Those who use them and practice them in their daily lives achieve success and happiness against all odds. Unfortunately, most groups of people overemphasize what people cannot do. This constitutes

one of the roots of the unnecessary challenges that society essentially puts on top of itself. The reality is that everybody has challenges and everybody deserves dignity and respect. Those who work in disability advocacy cannot emphasize inclusion, respect, and service enough. As a person with Asperger's Syndrome, I cannot either! On a more positive note, Nevertheless, those who have challenges and bravely embrace them every day serve as an inspiration to anybody; not just their like-minded peers. Minority groups, as underrepresented as they are, make the human race extraordinary. Without minority groups, communities would not thrive in vast quantities or with the pure quality that make them noble and notable change-making agents. My questions to you, whether you have a disability or not: - What are the power statements that comprise your anthem? - How can you share this anthem with others to make a difference in your world and THE world?

#### **Top Idea #2: Roommate Location Service**

5 Up Votes | 0 Down Votes | 5 Net Votes

Many of our young adults are having a hard time finding housing on their own while working part time jobs because they just don't make enough money. The lack of social activities and the ability to meet people makes it hard for them to locate suitable roommates. I would like to see a service that could match potential roommates and facilitate them meeting one another to gauge compatibility. Several roommates pooling resources could share housing and whatever supports they may require.

#### Top Idea #3: Becoming independent

5 Up Votes | 0 Down Votes | 5 Net Votes

Something that I've learned in becoming more and more independent is that it's hard to do it alone. Don't be afraid to ask for help, it doesn't mean you're weak

#### Top Idea #4: Addressing Barriers to Independence

4 Up Votes | 0 Down Votes | 4 Net Votes

Find out what resources are available to enhance independence. For example, some people with disabilities may be eligible for Personal Care Assistance, special transportation, etc. Also look into what assistive technology could help.

#### Top Idea #5: Concerns about Individuals with Autism

4 Up Votes | 0 Down Votes | 4 Net Votes

My concern is that policy wise, the federal government is not adequately prepared to meet the transition needs of young adults with autism. Once a young adult with autism finishes high school there is what I refer to as a "cliff" where there is a lack of availability of high quality home and community

based services and supports to help them transition. My last idea applies to what I am saying about Individuals with Autism and well as any other underserved population.

#### Conclusion

Through the <u>YouthACT Transition Truths National Online Dialogue</u>, ODEP and the National Collaborative on Workforce and Disability for Youth successfully leveraged leading-edge crowdsourcing tools to engage youth and young adults with disabilities in a virtual conversation on ideas for policies and best practices to support transition to adulthood.

In summary, the online event attracted more than 760 visitors, of which 453 participated posting 74 unique ideas, 347 comments and 609 votes. This metrics report provides a summary of the online dialogue's results, and the input and responses of the participants are now being analyzed in an effort to inform federal policymaking decisions. These results will help policymakers and people who work with youth with disabilities to better understand what supports they need to become successful adults.