



connecticut state  
innovation model

# CT SIM CAB KIDS AS SELF ADVOCATES LISTENING SESSION REPORT

ST. THOMAS SEMINARY, BLOOMFIELD: MAY 13, 2017

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NORTH CENTRAL REGIONAL MENTAL HEALTH BOARD  
151 New Park Ave., Hartford CT 06105

## CT SIM CAB KIDS AS SELF-ADVOCATES LISTENING SESSION REPORT

### EVENT OVERVIEW

On Saturday May 13, 2017, PATH Parent to Parent/Family Voices of CT (PATH/FVCT) and CT Kids as Self Advocates (CT KASA) organized an all-day youth summit at the St. Thomas Seminary in Bloomfield, CT. The theme was “Building a Great Life” and over 80 young adults and their caregivers came, representing the youth with disability community. The event kicked off with registration and a full complimentary breakfast in the main room. There was side room featuring community partners, full of resources, services, and supports for youth with disabilities. Snacks and lunch were also provided.

The forum offered opportunities for participants to hear from motivational young adult speakers Michael Scanlon and Xavier Farrell, listen to their peers speak on a panel about finding meaningful employment, and engage in a Social Media Healthcare Town Hall discussion. The Social Media Town Hall was sponsored by the CT State Innovation Consumer Advisory Board (SIM CAB) of which Nanfi Lubogo, Co-Director of PATH/FVCT, is a member. As part of their consumer engagement activities, the SIM CAB wanted to engage young adults in healthcare discussions – particularly those with disabilities. The Social Media Town Hall offered a space for youth to discuss their healthcare concerns and learn from each other. To include all youth regardless of ability to communicate, the Town Hall was structured with 3 modes of engagement:

- Verbal communication through the assistance of a moderator
- Visual supports to engage non-verbal participants
- Social media



“Through the use of focused questions and visuals and social media, we had some teens who, because of the nature of their disability, had never been able to participate in a group discussion before. On this day no-one was left out!” Said Carmina Cirioli, Co-Director of PATH/FVCT.

Throughout the day, youth actively participated on Facebook Live, Twitter, Snapchat, and Instagram. The Social Media Town Hall highlighted the use of social media and ensured that the youth voices via social media were included in the discussions. Regarding the use of social media, youth had lots to say. “We wanted the summit to be bigger than whoever was in the room” said Emily Ball, one of the CT KASA members. “As a person with a disability, I think it is harder to find a relatable group to share information in real time,” continued Ball. “Social media really helped us with that.”

Derek Hall from the Discovery Center facilitated the Town Hall discussion while Lisa Nee (PATH/FVCT) offered visual support. Quyen Truong (SIM PMO) tweeted live and Jessica McKenty (UConn UCEDD) managed the Facebook Live Discussion. Young adults shared many insights about their experiences with healthcare.

Youth shared personal experiences battling stigma and ignorance in school, and encouraged their peers to be courageous and to keep working towards living their lives in pursuit of their goals. Young adults were open about their struggles with mental health, with independence, and with navigating the healthcare system. A lot of attention was paid to ensuring that every young person had an opportunity to participate in the town hall. To ensure this, facilitator Derek Hall walked throughout the room to engage everyone. Lisa Nee’s visual support ensured that non-verbal young adults could share pictures to represent their thoughts and actively participate in the discussion. Social media,

including Facebook and Twitter, engaged more quiet youth who preferred to share their thoughts online; Quyen shared notable tweets with everyone. Many CAB members were also present in the room and some participated via social media.

Participants also practiced healthy practices like yoga and deep breathing, and gave each other support throughout the day. The event was organized by PATH/FVCT's youth leadership CT KASA, who aptly highlighted different issues faced by young adults with disabilities, and who celebrated the diverse voices of young people everywhere.

At the end of the event, many young adults expressed their gratitude to the adults and agencies that supported their vision. Next year, these young adult organizers want the Town Hall to be even bigger. Planning for the next summit is already underway with a proposed date in October 2018.



Photo Credit – J. Avery Wham. For more pictures click on the following link: [2nd Annual Youth Summit 2017](#)

## KEY FINDINGS:

1. Youth with disabilities have a lot to say, and offering a variety of mediums through which they can communicate facilitates their ability to share their perspectives
2. Social media is a forum on which young adults with disabilities can connect and share their experiences
3. Access to healthcare for young adults with disabilities most often involves their caregivers, who also need support
4. Transportation is a big barrier for many young adults with disabilities
5. Young adults with disabilities have an interest in learning about their healthcare in order to be independent
6. The KASA community facilitates friendships and fosters healthcare access

## WHAT WE LEARNED:

Youth shared personal experiences battling stigma and ignorance in school, and encouraged their peers to be courageous and to keep working towards living their lives in pursuit of their goals. Young adults were open about their struggles with mental health, with independence, and with navigating the healthcare system. Some key messages from the Tweetchat and Social Media Town Hall include:

- “Failing forward -- learning and improving from your mistakes. Getting better through each experience.” – Michael Scanlan
- I use the internet for my health
  - “Beware! Going on the computer too much during the day and/or late at night, you'll most likely wake up after 5-7 hours sleep”
- Most people believe they are responsible for their own healthcare: "I know myself the best and I know my issues the best"
- How comfortable are you discussing your mental health? = Very uncomfortable!!!!
  - I am somewhat comfortable but it is awkward at times honestly
  - Some people feel very comfortable due to support in school, others don't feel comfortable because of where counselors located

- My school severely lacked in helping me with my mental health issues. School was one of the biggest stressors
  - Get more acceptances of mental health related issues in the media
  - People can be judgmental because of ignorance.
- "I am comfortable & confident explaining my disability. But, sometimes I get nervous. The confidence is courage"
  - "Empathy - people need to put themselves in other people's shoes and understand that everyone is different. Need awareness."
- "You are who you are, and who you choose to impact" - Xavier Farrell
- "Taking care of my health is taking care of my dreams"
  - "Be prepared, have a health plan!!"

### CHALLENGES ABOUT HEALTHCARE:

Young adults at the event were not completely comfortable discussing their mental health. They feel that this discussion can be awkward. A lot of the discomfort around accessing mental health care corresponds with the location of counselors at their schools, and students' comfort with going to this location. One person shared that "My school severely lacked in helping me with my mental health issues. School was one of the biggest stressors."

Young adults with disabilities are also somewhat comfortable explaining their disability, and even the most confident sometimes gets nervous. Young adults wanted empathy and an understanding of people's differences, and an awareness of different disability issues and how they can manifest.

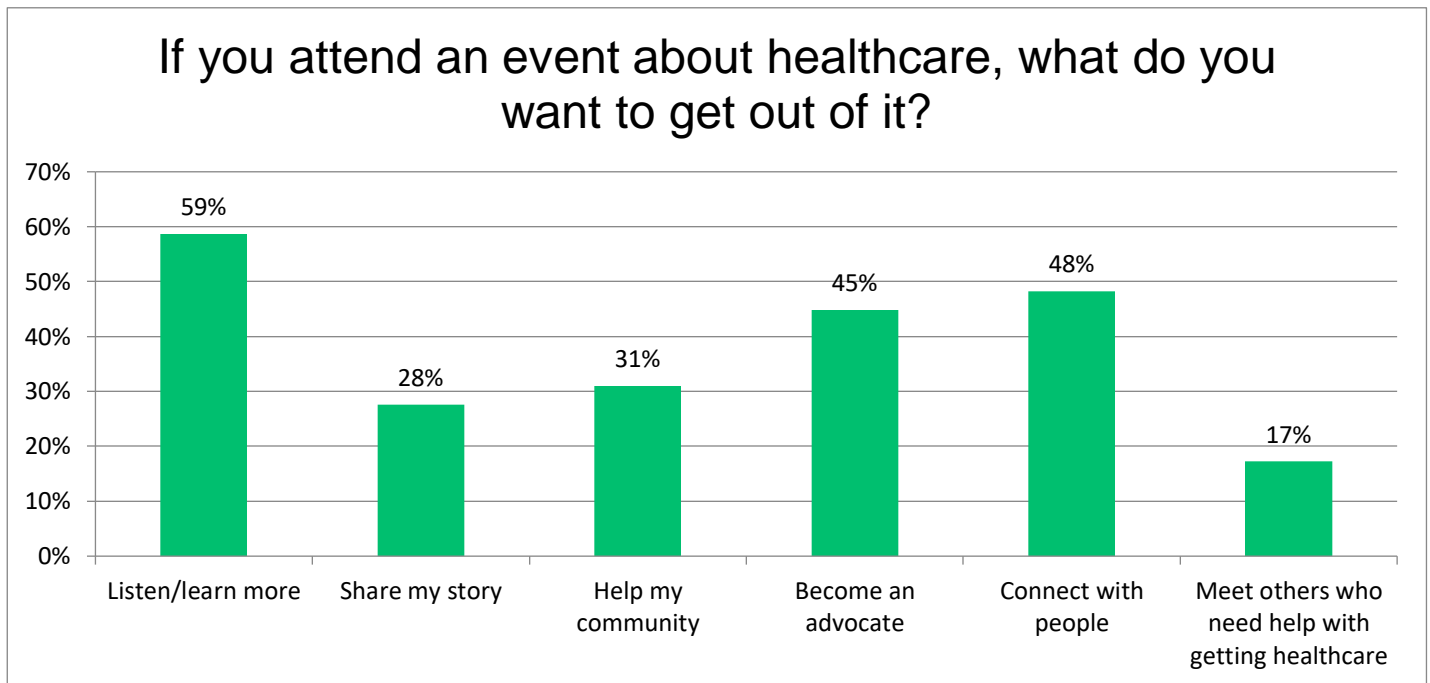
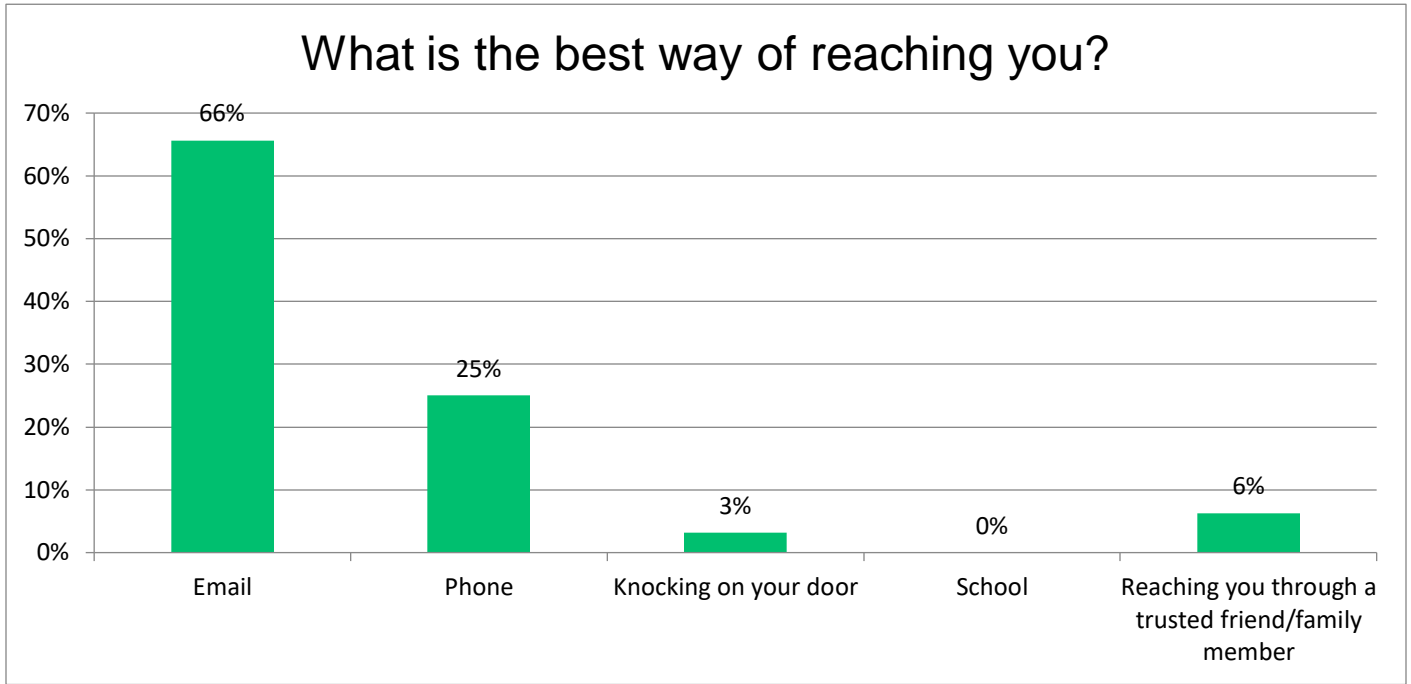
### SIM CAB FEEDBACK:

- Involve a young adult with disabilities on the SIM CAB
- Organize more forums that involve young adults with disabilities

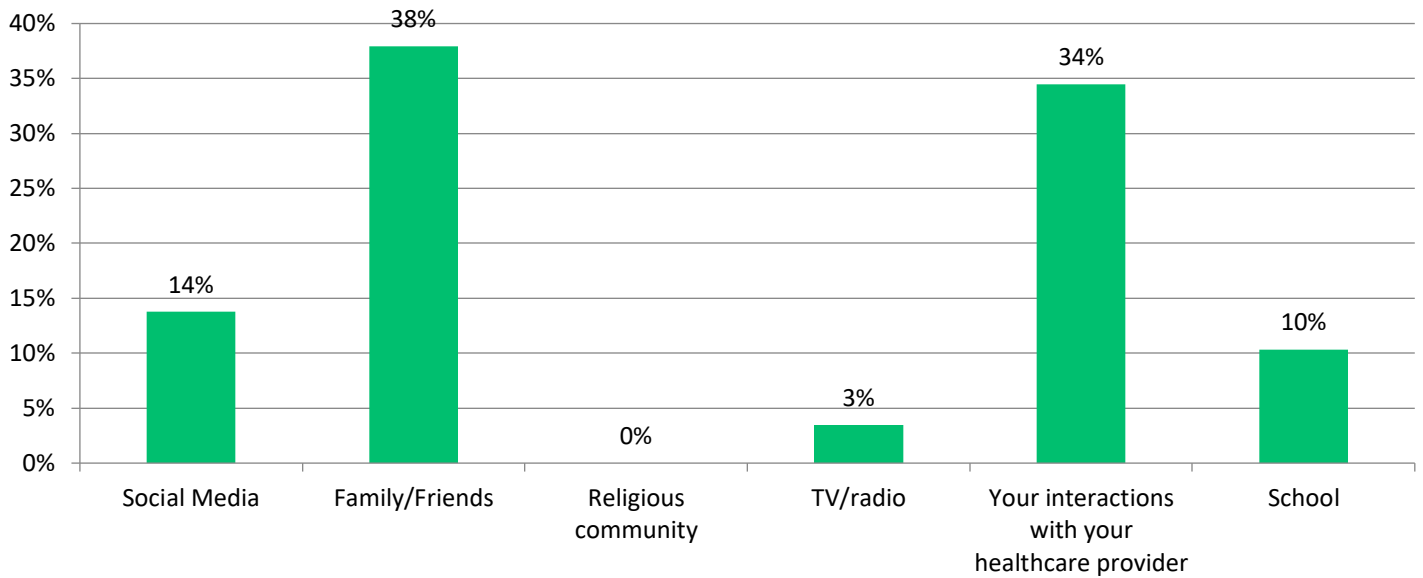
### RECOMMENDATIONS:

Below are some suggestions from youth for future summits:

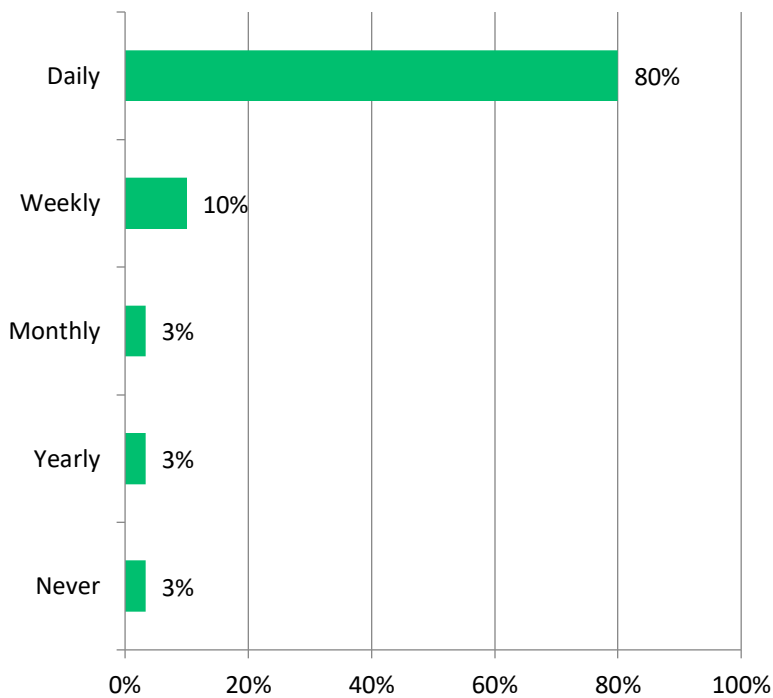
- Offer more interactive opportunities at tables with groups/teams
- Organize a project at the end of the summit to have closure
- Have available a poster paper for each group, to reflect on each breakout session
- Have each person create a self-portrait to represent themselves
  - Facilitate a discussion around the portraits that show that inside we are not so different at all!
- Invite a healthcare provider: a doctor and/or a health insurance company
- Have more time to learn about healthcare
- Get more High school students from local schools involved
- Including YouTube Live as an option for social media
- Have a shorter summit
- Have better advertising for a bigger group to participate.



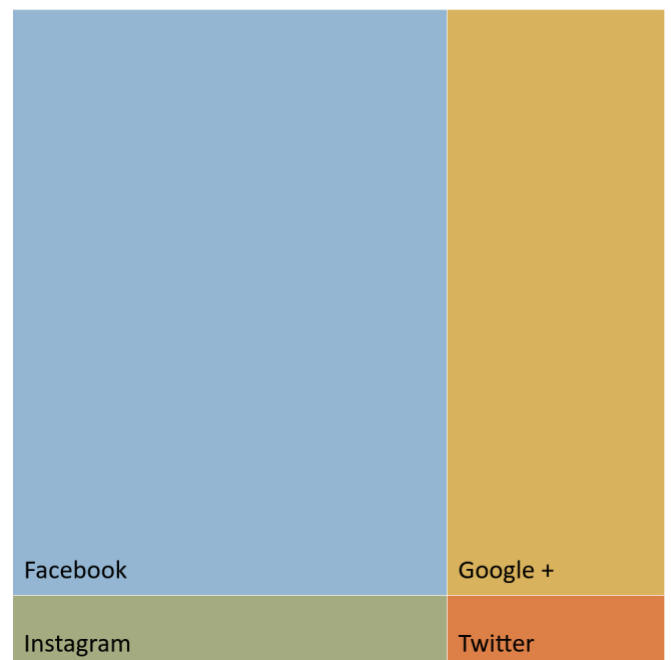
## What affects your understanding of healthcare most?



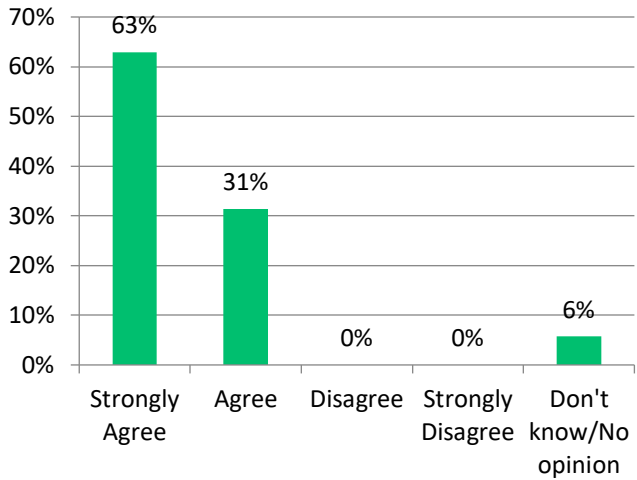
## How often do you use social media?



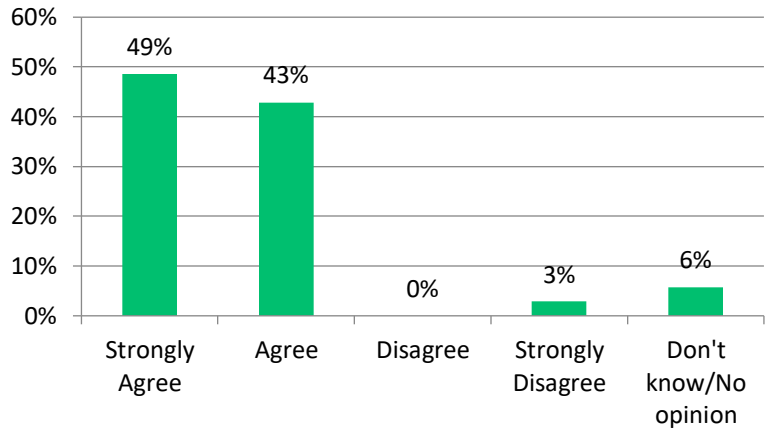
## What would you most likely use to learn about or talk about healthcare?



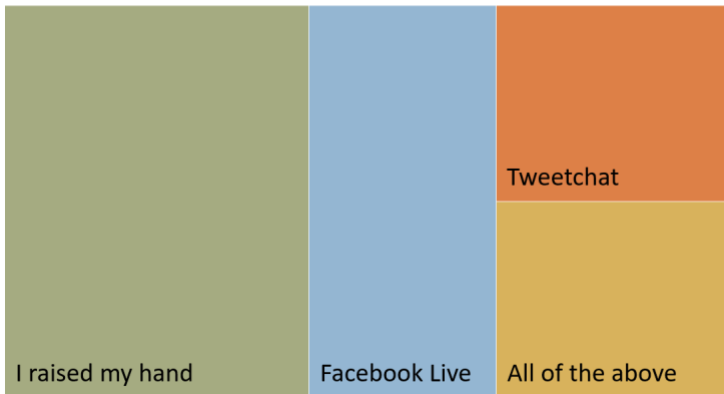
### The Social Media Town Hall was interesting



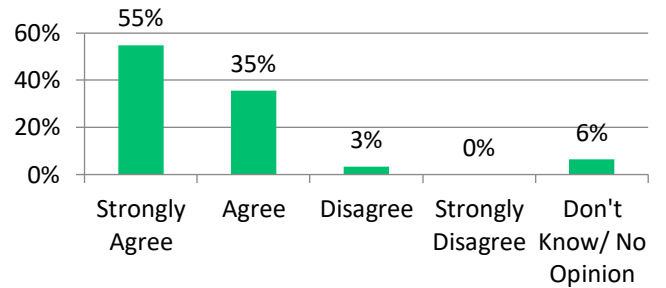
### The Town Hall provided useful information about healthcare



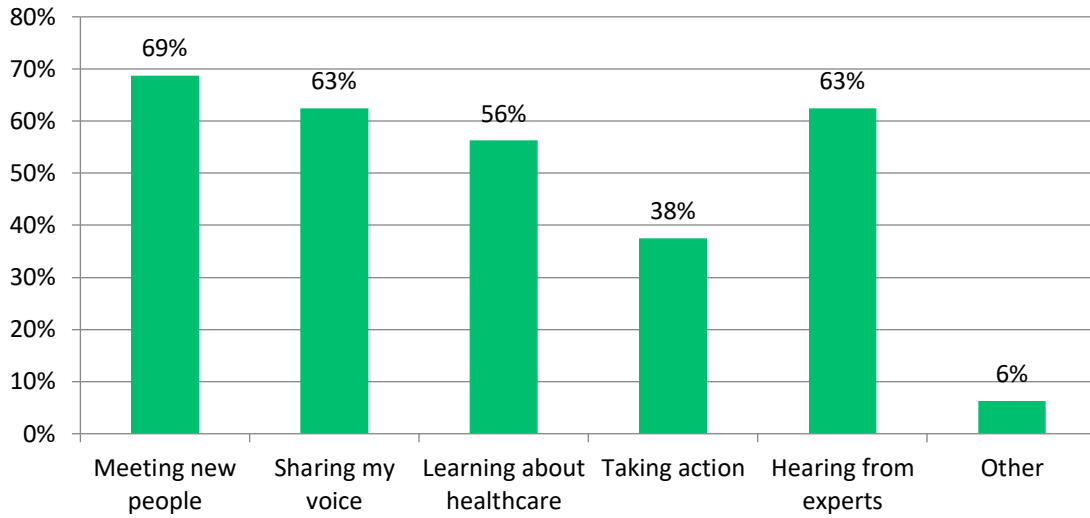
### I participated in the Social Media Transition Town Hall by:



### The visual supports provided helped me to participate in the Social Media Town Hall



## Describe what you like most about this Building a Great Life Youth Summit?



## Which of the following best describes you?

