

## How We Made It Happen: Interviews with Parent Leaders about their Kids Going to College

By Deborah Leuchovius and Sean Roy

In 2016, PACER Center, a partner of the Think College National Coordinating Center, conducted interviews with parents of youth with intellectual and developmental disabilities (IDD). These parents had played key leadership roles in establishing postsecondary education (PSE) programs for students with IDD. Five parent leaders, from five different states, participated.

### Interview Questions

- Have you always been active in advocacy, educationally or otherwise?
- How did your children inspire your efforts to create a new inclusive higher education initiative? What were the specific program components you wanted out of a PSE program for your son or daughter, and why? What impact did attending the PSE program have on your son or daughter's education and personal growth?
- How did you learn about PSE options for students with IDD? What types of PSE options for students with intellectual disabilities existed in your area?
- What did you do to get the ball rolling? What was the one thing that got everything started?
- Who were some of the key partners that helped in your efforts to create a new inclusive higher education initiative? What role did they play in the success of your activities?
- What was one challenge or barrier you encountered that you didn't anticipate?
- What mistakes (if any) did you make as you were working to get a new college option in place? What would you do differently?
- What are the 2 or 3 key pieces of advice you would have for any family member wishing to start an effort to create a new inclusive higher education initiative?
- What would you do to engage other families that are not as experienced or active in advocacy for college?

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**“I knew if I was going to make a better world for my daughter, I had to work to make the world a better world for everyone.”**

**—Gerard Jimenez**

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The PSE opportunities that resulted from each parent leader's efforts varied. One parent's efforts began with a friend offering classes to youth with Down syndrome at a community college. Two parents were instrumental in getting programs established at the universities where they worked. One parent's efforts resulted in five unique programs in his state.

Three mothers and two fathers were interviewed. Although each parent's experience was different, some common themes emerged. There was also some consensus on the approaches that they would recommend for other parents and advocates to use to establish more inclusive postsecondary programs for youth with IDD.

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### ABOUT THE PARENT LEADERS

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Each parent had a son or daughter with Down syndrome or on the autism spectrum. All had high expectations for their children with and without disabilities, placed a high value on education, and started “thinking college” from an early age. One parent and spouse invested in a prepaid community college savings program for their daughter with Down syndrome before she had even started kindergarten.

This commitment to education provided the foundation for each individual's effort to create a higher education program that would meet the needs for students with IDD in their communities. As one parent said, “I knew if I was going to make a better world for my daughter, I had to work to make the world a better world for everyone.”

In addition, most of the parent leaders interviewed had highly motivated youth whose dreams about going to college served as an important catalyst for working towards higher education opportunities for youth with IDD.

Each person interviewed was an experienced advocate on behalf of their children, and their children were often trailblazers in their communities. All the parents had experience working with state and local advocacy organizations in executive leadership, board, or programmatic positions. Several were graduates of Partners in Policymaking, a leadership and advocacy training program that teaches individuals with IDD and their family members to become community leaders and catalysts for systems change.

Most of the parents had professional or personal connections to the National Down Syndrome Society (NDSS), an organization that has provided national visibility and leadership on the need to create more higher education opportunities for youth with IDD. All shared a passion for learning and stayed abreast of the latest information about evolving best practices for youth with disabilities.

When the NDSS, the Association on University Centers on Disabilities (AUCD), and Think College began promoting higher education for students with IDD, these parent leaders were inspired to take action.

Attending the State of the Art Conference on Postsecondary Education and Individuals with Intellectual Disabilities was an important learning event for all five parent leaders. Since 2009, the conference has been held annually in northern Virginia. It brings together hundreds of families, policy-makers, and program members interested in advancing the field of PSE for young adults with intellectual disabilities.

## THE PROCESS

All the parent leaders are college graduates, some with multiple degrees, as well as avid learners who devoured everything available on models of PSE programs for students with IDD. All were in circumstances that allowed

them to invest a great deal of time into the project. One person ran his own business and could turn over responsibilities to his staff. Two individuals worked in leadership positions for state/regional advocacy organizations that embraced this issue as their own. The other two individuals worked for PSE institutions, and persuaded upper-level management there to start programs. All reported investing a significant amount of time over three to five years to establish these programs.

All used a variety of personal networks – including their legislative connections – and spent at least a year sharing information, building visibility, holding awareness events, and creating an alliance of key stakeholders across the state. Parent interest grew by word of mouth.

It was not difficult to generate support. “Each person you talk to becomes part of your network of supporters,” said one parent leader. “The amount of interest grows exponentially.”

Awareness events brought parents, postsecondary stakeholders, and allies from local and state education agencies, vocational rehabilitation (VR) agencies, and developmental disabilities (DD) programs together, and generated excitement about having PSE program options available to youth with IDD. Think College tools and resources, such as the video “Rethinking College,” also played crucial roles in this awareness and coalition-building process.

## TURNING INTEREST INTO COMMITMENT

The interviewees agreed that while the programs would eventually become self-sustaining through tuition fees, seed money to get started was important.

Funding was obtained in different ways. One individual formed an organization with a board of directors, and each board member was expected to contribute funding to support planning activities.

Some state activities were funded from the budgets of local advocacy groups that used their funds to bring in technical assistance consultants from Think College or NDSS to help them build capacity and begin planning.

Several projects applied for and received U.S. Department of Education Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) grants. These grants support the creation or expansion of high-quality, inclusive transition and postsecondary programs for students with IDD.

Recipients reported that TPSID funding not only provided money, but also structure, technical assistance, and credibility. However, these grants are made to institutions of higher education or consortia of institutions, not to nonprofit or ad hoc advocacy groups. Parent leaders had to bring decision-makers from institutions of higher learning on board to apply for TPSID funding.

Perfecting their “pitch” in order to get initial buy-in from postsecondary or legislative decision-makers was a crucial contribution these parent leaders made to their projects. All parents recommended using the Think College “Rethinking College” video in these efforts. As one put it, “A picture is worth a thousand words.” In addition, as another parent said, “Once administrators see that people are already doing this successfully in other states, they are more likely to ask why it is not offered here.”

### There were several points of guidance that emerged from the parent interviews.

- Reach out to mentors--don't do it alone.
- You need to know how to partner with others.
- Use Think College resources and staff.
- Contact your area University Center for Excellence in Developmental Disabilities (UCEDD) to help make the case with potential postsecondary partners.
- Educate, educate, educate is the way to address unwillingness to participate.
- Persevere – systemic change is slow – systems want to solve programs before starting rather than learning as you go along.

Two individuals interviewed were very familiar with their state legislative process and successfully approached state legislatures for funding. (In one case, the legislature overrode the governor's veto to enact the funding.) Once funding was obtained from the legislature, colleges that had been hesitant to commit were ready to move forward.

## STEPS TOWARD CHANGE

A Think College publication titled *Using a Change Model Approach to Guide Development of an Inclusive College Experience for Students with Intellectual and Developmental Disabilities*<sup>1</sup> outlines an eight-step change model used by the planning team of the University of Central Florida. The eight-step process includes the following:

- 1) Establish Urgency**
- 2) Form a Powerful Coalition**
- 3) Create a Vision for Change**
- 4) Communicate the Vision**
- 5) Remove Obstacles**
- 6) Create Short-Term Wins**
- 7) Build on the Change**
- 8) Anchor Changes in Culture**

The stories that each parent leader told about their own efforts in creating change closely mirror this change model. They shared tips and strategies for each of the eight steps in the process.



## 1. Establish Urgency

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- Build support by letting people know what is going on nationally.
- Collect data – do a study, survey, focus groups – the data becomes basis of a statewide plan.
- Don't wait for people to get on board to get started – structure a course for students with IDD to show how it works.
- Bring in outside speakers to build excitement.

## 2. Form a Powerful Coalition

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- Work with family organizations.
- Build a coalition of parents, advocates, and organizations through local and state awareness events.
- Get youth involved in your advocacy efforts. Youth allies were very useful in our work, both the voices of self-advocates and their typical peers.
- Present with youth at school board meetings and to foundations—the personal impact of postsecondary programs on individual youth or self-advocates expressing their desire to go to college can be very powerful, plus giving ownership of the issue to self-advocates is the right thing to do.
- Build support, bring in key stakeholders, hold a community forum.
- Identify high school teachers who are interested.
- Look for parents who are influential and can open doors [to partner organizations, postsecondary institutions, the legislature].
- Raise money for postsecondary institution, not just your own program.
- Get people together, grow numbers, make a plan.

## 3/4. Create a Vision for Change / Communicate the Vision

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- Courting the press is important.
- Be a visible champion, put a face to it.
- Demonstrate how program aligns with university mission statements – to serve state or community or diverse populations.
- Develop a presentation you know people will listen to.
- Use data to support your vision.
- A picture is worth a thousand words, so use the Think College video, “Rethinking College.”
- Make your own videos to bring it to local level; these can then be blended with the great national resources.
- Capitalize on [the individual connections of the individuals] who step up.
- Bring young people to testify to the legislature and others.
- Faculty need to understand the what and why of the program.
- Be intentional about conveying parent support for student self-determination. Parents who are eager to help their sons and daughters with IDD pursue postsecondary education opportunities have perspective. They are looking at their youth's unrealized potential, and know that high expectations are not unrealistic expectations.

## 5. Remove Obstacles

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- Work with existing postsecondary education structure – let the colleges do their thing.
- The Disability Resource Center is your friend.
- Solicit funding from parents who have means.
- Approach foundations.
- Approach your state legislature:
  - > First get legislature to endorse concept – then ask for funding at a later session/year.
  - > Alternatively, put in the legislative budget, don't bother with a bill.

## 6. Create Short-Term Wins

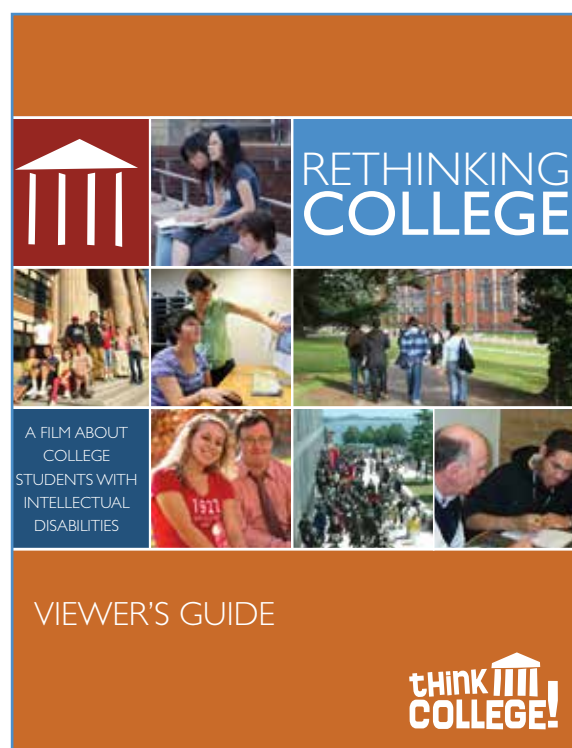
- Celebrate the number of youth and parents you are reaching.
- Celebrate the exponential growth of your network.
- Spread positive experiences by word of mouth.
- Hold an annual state conference featuring best practices in higher education for students with IDD.

## 7. Build on the Change

- Provide more ways for more families to learn about the vision – and attend the national State of the Art conference.
- Partnerships with state and local education agencies are underutilized – improve school district role.
- Explain concept to foundations so that this doesn't seem such an outlandish idea to influential change-makers, because it still is to a lot of people.
- Capitalize on increased state Olmstead activities and awareness.
- Build strong self-advocacy skills in high school.
- Serve elementary and secondary students with disabilities in inclusive classrooms so they will be better prepared for college experience.
- More training needs to be provided for tutors and mentors.
- Need to focus on time between classes, how to manage freedom and independence.
- Expand course options.
- Look at what other states are doing.
- Stay connected to the budget and the priorities so that the voice of empowered parents can be an asset to the work as it moves forward.
- Remain involved if projects seek additional funding to ensure the family voice continues to be influential.

## 8. Anchor Changes in Culture

- Seek legislative support and funding.
- Align your program goals with university mission statements.
- Argue program will provide income for college.
- Work within the existing postsecondary structure.
- Work out which ongoing supports for students will be funded through VR and DD programs, e.g. tuition, peer mentors, etc.
- Power shifts quickly once budget is in the hands of a bureaucracy and negotiating ongoing parent involvement roles is important.



### RETHINKING COLLEGE:

The film is available at  
[www.thinkcollege.net/rethinking-college](http://www.thinkcollege.net/rethinking-college)  
 along with a downloadable guide for  
 suggested film use.

## CONCLUSION

Young adults with IDD should be able to access postsecondary education regardless of where they live. While the number of PSE opportunities that meet the needs of students with IDD is increasing, there remains an unmet need for the development of new programs and broader dissemination about them. Tapping into the energy and commitment of parents can help make this change happen.

The experiences of the parent leaders we interviewed demonstrate the key roles that parents have played in the launch of new programs in their own communities at the dawn of the “Think College” national movement. The parent leaders interviewed for this paper were well seasoned and well connected advocates; however, not uniquely so. Their insights yield a range of strategies that individuals, advocacy groups, and postsecondary institutions can use to inform, inspire, and involve more families in making the vision of new PSE options for students with IDD a reality throughout the U.S. and beyond.

Hines, R., Meyer, A., & Donehower, C. (2016). Using a change model approach to guide development of an inclusive college experience for students with intellectual and developmental disabilities. *Think College Insight Brief*, Issue No. 28. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

<sup>1</sup> Based on a 1999 Supreme Court decision, *Olmstead vs. L.C.*, all states are required to have a plan to eliminate unnecessary segregation of persons with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs. For example, states are serving more and more individuals with disabilities in home and community-based instead of institutional settings, and focusing on finding work for individuals in the community rather than in segregated settings such as sheltered workshops.

## ABOUT THE AUTHORS

Deborah Leuchovius has worked at PACER Center on disability rights and transition to adulthood issues since 1992.

Sean Roy, co-director of PACER’s National Parent Center on Employment and Transition, has been at PACER since 2001. Both are family members of individuals with IDD.

The following individuals were interviewed for this article. All indicated that they are willing to talk with other parents about establishing a postsecondary education program for youth with IDD.

- Donald Bailey, dbailes@bellsouth.net
- Mary Bryant, mhbrant@unr.edu
- Angela Jarvis-Holland, angelajarvisholland@gmail.com
- Gerard Jimenez, gerardatx@gmail.com
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### INSIGHT, Issue No. 30, 2016

INSIGHT is a publication of Think College, a project of the Institute for Community Inclusion at the University of Massachusetts Boston, funded by the Office of Postsecondary Education (Grant No. P407B15002). The opinions contained in this document are those of the grantee and do not necessarily reflect those of the funders.

Recommended citation for this brief: Leuchovius, D., and Roy, S. (2016). *How We Made It Happen: Interviews with Parent Leaders about their Kids Going to College*. Think College Insight Brief, Issue No. 30. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

