

The Makor College experience: Successes and challenges in the first years of a college experience program for individuals with intellectual disability

Stephen Glicksman*, PhD

Makor Disability Services and Yeshiva University,
New York, New York, USA

Abstract

Recent decades have shown a tremendous increase in post-secondary education programs for college aged students with Intellectual and Developmental Disabilities. The Makor College Experience, a three-year, non-degree program on the campus of a private university, is one such program. This paper shares some insights that were discovered as the developers of this program attempted to overcome the challenges of including students with ID on a college campus, addressing issues such as the dialectic between being “rights-based” and “person centered,” as well as coping with the “misguided kindness” of staff and fellow students who, with the purest of intentions, tolerate inappropriate behavior of participants in the program in a manner that, in the long run, may actually hinder their growth and acceptance in the outside world.

Keywords: Intellectual disability, intellectual and developmental disability, postsecondary education, college, inclusion

Introduction

Recent decades have shown a tremendous increase in postsecondary education programs for college aged students with intellectual and developmental disabilities (ID). Currently, there are over 270 college programs with individuals with ID listed in the ThinkCollege.net database (1), in settings ranging from technical schools to large universities. Most of these programs share the same stated purposes, and their students share the same stated goals: To provide students with ID opportunities for greater independence; to improve social skills; to develop valued social roles; and to have the normalized experience of being, “just like everyone else” (2, 3).

* **Correspondence:** Adjunct Associate Professor Stephen Glicksman, PhD, Developmental Psychologist, Director of Clinical Innovation, Makor Disability Services/WLCR, 1556 38th Street, Brooklyn, 11218, New York, United States. Email: sglicksman@makords.org

While being “just like everyone else” is a laudable goal, it is equally true that “everyone else” is not necessarily treated the same way across settings, nor is it true that “everyone else,” even in settings aimed to promote inclusion, treat people with ID in the same way they treat their neurotypical peers. This is true in many areas, but is a particularly important variable to consider when developing programs for individuals with ID in settings where their historical exclusion is, for lack of a better term, logical. In other words, while the social and cultural experience of going to college is desired by many with ID, the exclusion of people with ID from advanced academic settings can hardly be described as “discriminatory.” For that reason, inclusive postsecondary educational programs need to take into account not only the desires of the students they serve, but the realistic impact that their diagnoses may have on their social, vocational, and academic growth within the context in which the programs are being developed. The dialectic of the equally valid rights-based and person-centered approaches (5) and between equality and equity (6) should be considered when asking questions such as whether students with ID should, for example, be auditing classes with their neurotypical peers that they may be incapable of following so that they “feel like” they are in college as opposed to insisting that program participants be provided with only developmentally appropriate academic experiences in a more self-contained setting, or whether it is better to have someone with disabilities be the stereotypical water boy on the university’s basketball team even if such opportunities in fact keep those with ID in the perpetual “one-down” position as opposed to supporting the individual to feel comfortable cheering the team from the stands, “just like everyone else.”

With these questions in mind, we would like to share some lessons learned during the first years of a unique college experience program for individuals with ID on the campus of a private, four-year college. We begin with a brief description of the program itself, followed by a discussion of these lessons with the hope that an acknowledgment of these challenges, and how we overcame them, can serve as a model for others who hope to replicate the success of our program in their own settings.

The Makor College experience

Opened in the Fall of 2017, the Makor College Experience (MCE) is a three-year, non-degree, college experience program on the campus of Yeshiva University for individuals with ID. Students typically range in age from 18 years to 25 years, although some students for whom this program was a “lifelong dream” began attending in their thirties. The program is a partnership between Yeshiva University and Makor Disability Services, a lifespan social services organization meeting the needs of people with intellectual and developmental disabilities since 1978. The program is technically a Day Habilitation Without Walls run by Makor Disability Services under the oversight of the New York State Office for People with Developmental Disabilities (OPWDD).

In other words, Makor Disability Services pays Yeshiva University a fee to run its program on their campus; in return, the program receives classroom and office space; access to campus resources; and the opportunity to take part and be included in campus life. The program itself mirrors a typical Yeshiva University day, which in and of itself is somewhat unique. Yeshiva University is the oldest and largest private university under Jewish auspices, and is a combination of both a modern research university and an academy of Jewish studies. The undergraduate schools of the university offer students a dual curriculum, engaging in Jewish religious studies in the morning followed by a full secular college course load in the afternoon. The MCE duplicates this model, with MCE participants engaging in self-contained classes exposing them to religious studies in the morning and secular studies in the afternoon. The afternoon classes generally focus upon life skills, liberal arts, and planning for students’ futures after the program. The academic portion of the program places a heavy emphasis on vocational exploration, with Year One focusing on prevocational and job readiness skills; Year Two focusing on professionalism and off-campus career exploration outings; and Year Three focusing on concrete futures planning and resume building. Career planning is developed with the assistance of the faculty and a Vocational Coordinator based on personal interest, skills and abilities, and employment potential. A residential component to

the program takes place in near-campus housing, allowing students to take full advantage of campus resources and inclusion opportunities in the evenings. MCE students are involved in student clubs; make use of the pool and gym; attend campus events; and are generally seen as fellow students by their typically developing peers. Students leave the program with a certificate of completion.

Lessons learned

Since its inception, many philosophic, educational, and legal hurdles had to be overcome, such as how to include MCE participants in student life even though they are not technically students (resolution: We have student IDs, but not student ID numbers) or how to make sure MCE participants view their own position as full-fledged members of the student community even though they are not taking classes with their college peers (resolution: Make sure MCE classes are meaningful and developmentally appropriate, and support non-academic inclusion opportunities). In overcoming these challenges, we have learned a few truths that we believe are worthwhile sharing, both for those interested in developing their own college experience programs as well as for any type of inclusive program aiming to serve people with ID in the community:

- Being real is the best way to avoid tokenism. As noted, there are currently over 270 programs for people with specialized needs on college campuses throughout the United States (1), many in New York. Nevertheless, when representatives from OPWDD came to our program and observed our students reviewing their lessons in the student study hall; or when we pointed out a poster on the wall advertising a club that had a photo of one of our students amongst the participants; or when we pointed out how some of our third-year students are now officers of student clubs; or how a college student-led initiative actually led to a change in the YU undergraduate constitution to allow our participants to vote in student elections even though, technically, they are not

students; and when they saw the YU students saying, “Hi” to the Makor students by name in the hallway; the representatives commented that they had visited numerous inclusion programs on campuses, but that ours was the first that did not smack at all of “tokenism”, meaning, that the MCE students appeared to be truly included and accepted as peers. We responded that we believe that lack of tokenism is by design: We join where appropriate, and we do not where inappropriate. We do not have participants auditing college classes they cannot understand. We do not engage in activities designed to have the participants of our program “feel like” they are going to college. Rather, we designed a program that actually provides our students with a college experience, on their level, meeting their needs, as well as meeting the needs of others. We have gone so far as to call student leaders of clubs that a number of our participants were interested in joining and saying, “Be honest- how many Makor students can come to this meeting without being overwhelming to the club?” and people have been honest with us (“We can handle three- more than that would be hard”). And we, in turn, have been honest with our participants about the need to take turns or find other interests. In other words, we do our best to avoid situations where the inclusion of Makor students would most likely be viewed as a “charity,” and focus on those areas in which our students are more likely to succeed as true peers. Which brings us to the second truth we have learned:

- Being real is the best way to support growth. Makor students are typically described as, “high functioning,” and have had many inclusive experiences in their lives. The term “high functioning,” however, is becoming somewhat controversial in some circles because it can be misleading: Makor students are “high functioning” compared to other people with ID; not, however, compared to a typical college student. The cognitive challenges of individuals described as having

“mild ID” are mild compared to the rest of the population with ID; they are significantly behind the typically developing population. The social communication challenges of individuals diagnosed with Autism Spectrum Disorder are, by definition, significant, however “high functioning” a person might be viewed when compared to others with the same diagnosis. Something we realized early in our program is that the people the program was designed to serve had primarily lived inclusive lives, and, partially because of that, were used to having many of their inappropriate behaviors tolerated. They were also very used to hearing the well-intentioned but not always realistic advice that, “You can be anything you want to be.” College, however, is a time to explore realistic options and to learn about one’s strengths and challenges in addition to one’s interests. Because the aim of our program is to launch our graduates into meaningful, competitive jobs in the real world, we are very open, and frankly blunt, about our students’ disabilities. In other words, we discovered that a primary task of our program is to help individuals develop what we refer to as an, “adaptive disability identity”. It is not uncommon to hear a conversation in which a staff member tells an MCE student, “That wasn’t really an appropriate way to behave,” or, “That wasn’t really an appropriate joke to tell,” and have the student respond, “But they let me sit with them,” or “But everyone laughed”. The staff member will then say, “Yes, but why did they laugh? Why were they nice?” only to have the student in return smile (or not smile) and say, “Because I have Autism?” What we have learned is that almost everyone on campus will welcome our students once; but, then it is up to the students, and the staff supporting them, to have them welcomed back a second time. Part of that support is being open and honest about our students’ strengths and challenges, something that we have realized many in our program have never truly experienced. That

lack of experience leads, we believe, to continuing inappropriate (yet historically tolerated) behaviors, as well as unrealistic or unhealthy expectations.

One area in which this comes up frequently is employment expectations. The ultimate goal of the program is to have our students graduate with job offers, and a lot of hours are spent in the program exposing the students to different careers and work environments in an effort to expand their horizons. It is interesting to note that most students enter the program wanting to either a) do what a successful relative does, such as being a doctor or an accountant; or b) work in a school. And, in fairness, we can understand why: Because, quite often, people’s dreams are limited by their experiences. In our program we often find ourselves not only trying to open the minds of our students to the wide variety of career options open to them, but equally importantly, we set up situations aimed to dissuade people from some of their current less realistic or maladaptive dreams. For example, we know that the reason many of our students want to work in school settings is because schools are an environment with which they are familiar and in which they feel safe. The reason we are not thrilled by people with ID wanting to work in school settings, however, is because we believe that in a school setting, a person with ID will always be viewed as a student and never an adult. Talking openly not just about a person’s dreams and rights, but about the whole person, including his honest limitations or how he is perceived by others, and then seeing how he can expand his dreams despite those limitations and biases are what we have found helpful in leading to true growth and what has supported our students in becoming more equally welcomed, realistic, respected, and independent. Which leads to the final truth learned:

- Very well intentioned people often just don’t understand. We once received a call from the head of the university’s dining services, informing us that a Makor student was flirting inappropriately with staff in the dining hall. We developed a behavior plan, part of which was that the student was no longer allowed to eat in the dining hall until

he showed staff that he was able to control this behavior (don't worry- there are plenty of other eateries around campus). When we informed the dining services staff of this plan, we received a response that said, "We don't mind him being here. He just requires supervision." While on its surface, this response shows a welcoming attitude on the part of the university staff, it also reflects a lack of understanding on the part of that staff to the goals of inclusion: If a person requires supervision to behave appropriately, that person is not independent. Furthermore, we believe the reason a Makor student would act in the manner this particular student did is because such behavior had been tolerated to some degree in the past due to, in this case, the person's Down syndrome. Furthermore, the response of the university staff implied that this person need not be taught how to behave appropriately. Rather, he simply needed to be kept from behaving inappropriately by providing apparently lifelong supervision. So, while accepting his presence in the dining hall may be an example of the university staff wanting to treat this student, "just like everyone else", the fact is that "anyone else" engaging in the targeted behavior would have been banned from campus at best and arrested for sexual harassment at worst. Because our student's Down Syndrome, in their attempt to treat our student "just like everyone else" (i.e., allowing him continued access to university facilities) the university staff were actually treating our student not only differently than everyone else in the moment, but in a manner that assumes and supports this differentiation for life (he is welcome only with supervision).

Interestingly, it is not just university staff and other civilians that have difficulty with the right-based/person-centered dialectic, but even regulators and those tasked with supporting individuals with ID in the community can fall into this trap. The near-campus housing in which students of the Makor program reside is an example of this. The

Makor House (as it is called) does not receive any funding from OPWDD. The reason for that is because regulations state that people with ID in new certified settings cannot reside with more than four people, as a residence with more than four individuals living communally is considered "institutional." In other words, according to current regulations, people with ID cannot live in a college dorm setting, because college dorms are institutions. This and other examples of typical college experiences not fitting into current service provision boxes is another aspect of well-intentioned people often creating barriers to actual inclusion in the name of protecting the rights of those with ID. These situations remain a paradox when developing programs that are not designed to fit neatly into current service provision paradigms.

Conclusion

There was a time when the greatest challenge to people with ID and the sentiments that we in the field had to fight against were those of prejudice, fear, and exclusion. Today, and definitely for the better, the sentiments we most need to fight against is misguided kindness, and inclusion as an "activity" as opposed to a reality. The challenges we have experienced in developing a college experience program for those with ID are often grounded in this idea. Nevertheless, the success of our program indicates that with forethought, honesty, and openness, these challenges can be overcome in a manner rewarding for everyone.

References

- [1] Think College. URL: <https://thinkcollege.net/about/wh-at-is-think-college>.
- [2] Plotner AJ, Marshall KJ. Postsecondary education programs for students with an intellectual disability: Facilitators and barriers to implementation. *Intellect Dev Disabil* 2015;53(1):58-69.
- [3] Folk ED, Yamamoto KK, Stodden RA. Implementing inclusion and collaborative teaming in a model program of postsecondary education for young adults with intellectual disabilities. *J Policy Pract Intellect Disabil* 2012;9(4):257-69.

- [4] Grigal M, Dwyre A, Davis H. (Transition services for students aged 18-21 with intellectual disabilities in college and community settings: Models and implications of success. Institute for Community Integration: University of Minnesota, Minneapolis, MN. NCSET Information Brief 2006;5(5).
- [5] Glicksman S, Goldberg C, Hamel C, Shore R, Wein A, Wood D, et al. Rights-based and person-centered approaches to supporting people with intellectual disability: A dialectical model. *Intellect Dev Disabil* 2017;55(3):181-91.
- [6] Piaget J. *The moral judgement of the child*. Harmondsworth, UK: Penguin Books, 1983 (First published 1932).

Submitted: January 05, 2020. *Revised:* January 28, 2020.
Accepted: February 11, 2020.

Copyright of International Journal of Child Health & Human Development is the property of Nova Science Publishers, Inc. and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.