

Digital Self-Help Groups for College Students with Dyslexia: What They Can Provide to Young People With Substantial Difficulties in Reading and Spelling on Their Path through Higher Education

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Higher education students with dyslexia are generally under enormous emotional pressure. The fear of getting exposed as “stupid” leads many of them to isolate themselves and avoid social contact with their peers. In consequence, a lot of dyslexic college students suffer from feelings of loneliness or even depression and anxiety. One promising way to palliate the anguish is participation in self-help groups. They can create a sense of belonging and of not being the only one out there with severe reading and writing problems. Moreover, they can help disseminate practical information on how to best cope with one’s challenges. In this paper, we describe the opportunities that digital self-support groups (mostly by means of video conferencing) can offer. We argue that for these groups to be successful, they need a facilitator, must limit their attendance to a specific set of not more than five members, should have some etiquette and routines, should not limit the number of sessions that one is allowed to attend, and should be connected with nonprofit associations or other suitable organizations to elicit synergy effects.

Keywords: dyslexia, higher education, emotional distress, digital self-help groups

GENERAL CHALLENGES OF HIGHER EDUCATION

To pursue a college education successfully is highly demanding. Upon enrolling at a university, students have to adapt to unknown surroundings and

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acclimate to a new lifestyle. While they used to draw on their families or long-time friends for support, they are now required to build up a new social support network. Thus, the transition from high school to college can be emotionally difficult. Still, even after years of living independently as a university student, the stress associated with high academic pressure, financial insecurities, and concerns for the future puts many young people on edge. Recent studies indicate that depression, anxiety, and loneliness in this population remain on a high level and are even on the rise (Nelson & Gregg, 2012; Roche, Holdefer & Thomas, 2022).

SPECIFIC CHALLENGES FOR COLLEGE STUDENTS WITH SEVERE READING AND WRITING PROBLEMS

The requirements of a university education can be overwhelming for any individual. However, the strains intensify for those who struggle with the tremendous amount of reading and writing needed to succeed in college. Students with difficulties in these areas are usually no less motivated, no less knowledgeable, and no less intelligent than their peers. In fact, because they have to rely more on their memory than others when trying to follow a presentation, their retentiveness is oftentimes especially well trained. While most young people can take notes or rehearse what has been discussed by reading a suitable paper or book chapter without too much effort, students who struggle with literary language depend highly on their ability to concentrate and to memorize as much relevant information as possible while sitting in a class or lecture. They oftentimes demonstrate remarkably strong reasoning and problem-solving abilities. However, the pressures of having to deal with reading and writing to such a large extent, as is the case in higher education, are frequently overwhelming and limit the chances of earning a degree (Fawcett, 2018; Osborne, 2018).

College students with dyslexia have to face an extraordinary amount of risk exposure in this context. While many young people find it difficult to keep up with the critical reading and writing requirements of the classes and lectures they attend, those with this diagnosis face a whole new dimension of challenges. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) by the American Psychiatric Association (2022), dyslexia “refers to a pattern of learning difficulties characterized by problems with accurate or fluent word recognition, poor decoding, and poor spelling abilities” (p. 67). It is viewed as a neurodevelopmental disorder caused by a complex interplay among genetic, epigenetic, and environmental factors that impact the ability of the brain to perceive and process verbal or nonverbal information efficiently and accurately. In standardized assessment instruments, individuals with dyslexia perform below average in the areas of decoding, oral language skills, reading fluency, text comprehension, spelling, and/or word recognition (Hatcher, Snowl-

ing & Griffiths, 2002).

Pinpointing the exact percentage of college students with dyslexia is difficult because the most recent update of the DSM-5-TR no longer contains separate criteria for this diagnosis. It is now lumped with other specific learning disabilities (Richardson, 2021). However, approximately 4% of all college students suffer from any kind of disorder that interferes with their ability to listen, think, speak, write, spell, or do mathematical calculations, with dyslexia being the most common problem (Pino & Mortari, 2014).

THE EMOTIONAL TOLL OF LIVING WITH DYSLEXIA AS A COLLEGE STUDENT

As mentioned above, young people in higher education generally face a high amount of emotional problems. According to the “Healthy Minds Study,” 31% of U.S. college students have suffered from anxiety disorders, 27% from depression, and 8% from psychological trauma (Eisenberg, Lipson & Heinze, 2021). Those with neurodevelopmental disorders such as dyslexia are, on average, considerably more anxious and more depressed than their peers. In addition, they often have extremely low self-esteem (Ihbour, Anarghou, Boulhana, Najimi & Chigr, 2021; O’Brien, 2022).

Because the ability to read and write properly is so pivotal in our society, failing in this regard is commonly associated with feelings of embarrassment and shame. Many individuals with dyslexia have a history of humiliation. In elementary and high school, they frequently experienced bullying, not only by classmates but also by teachers. Nearly everyone in their immediate environment was unaware that the brain of a student with dyslexia just cannot perceive the words on a page correctly. Having severe difficulty doing something that almost everyone else is proficient in can be extremely mortifying. What has been unsettling in elementary and secondary education becomes even more stressful in tertiary education. College students are a selected segment of the population in terms of intelligence, talent, diligence, and conscientiousness. Having to match with them gives further reason to feel pressured and to be in constant worry of getting presumably exposed as being “stupid.” The fear of being “found out” frequently causes students with dyslexia to isolate themselves from their peers, which intensifies the perception of being different from others in a negative way. In fact, loneliness seems to be the most painful effect of dyslexia for many individuals in higher education (Feldman, Davidson, Ben-Naim, Maza & Margalit, 2016; Ickson, Begerano, Levinson, Savariego & Margalit, 2021).

WAYS TO HELP COLLEGE STUDENTS WITH DYSLEXIA REACH THEIR POTENTIAL

Unfortunately, all too often, the chance for such college students to later make a substantial contribution to society goes to waste; this is because the pressure becomes so overbearing that many of them drop out of school. The list of prominent people with dyslexia and university diplomas who have

truly made an impact on humanity is long and impressive: Alexander Graham Bell, Albert Einstein, Pierre Curie, Jacques Dubochet, Galileo Galilei, Carolyn Widney Greider, John Robert Horner, Archer J. P. Martin, and James Clerk Maxwell, to name a few (Dyslexia Association of Ireland, 2022). What would have happened had these individuals, at some point, decided to give up on their ambitions is incomprehensible.

Institutions of higher learning are well advised to take precautions against letting the potential of students with dyslexia go unutilized. Fortunately, many of them run excellent disability services. Students can receive counsel on how to use different tools to compensate for their reading and writing problems (such as spellcheckers or text-to-speech software during exams). Such services can also help them request extended deadlines for papers or other assignments (Callens et al., 2012; O'Rourke, Connelley, Barnett & Afonso, 2020; Rath & Royer, 2002). In fact, there are different rankings for dyslexia-friendly universities, such as that by Best Value Schools (www.bestvalueschools.com/rankings/colleges-dyslexic-students), that provide orientations of venues that fit the needs of young people with learning disabilities in reading and writing. Some colleges also offer counselling aimed to remedy the psychological challenges often associated with this kind of disorder. However, even the best services of this kind may not lift the burden of feeling isolated from peers. Getting extra time in exams or receiving counselling does not rid students with dyslexia of the impression that they are all by themselves; the feeling of loneliness remains (Abbott-Jones, 2021).

SELF-SUPPORT GROUPS AS A TOOL TO MITIGATE THE STRAINS OF STUDYING WITH DYSLEXIA

Self-help groups are highly promising tools to address this challenge. They provide a forum for people with common problems to come together on a regular basis. The most distinguishing feature of such coalitions is the fact that peers help one another. No therapists create or manage formal clinical experiences. Everyone participates as a peer who struggles with the same issues as others (Graves, 2012; Kurtz, 1997; Leutenberg, Morris & Khalsa, 2012; Nichols, 2021). The main goals of self-help groups are to offer an opportunity for social contact, to extend informal support to one another, to encourage the participants to put the locus of control on themselves, and to emphasize interaction and growth. Gathering with people with similar challenges makes one realize that they are not alone and that there is an entire community who understands, empathizes, and relates to them. This insight alone can have an extremely uplifting impact on one's psyche (Finn, 1999; Vickery, 2022).

The first get-togethers that could be considered self-help groups in the aforementioned sense were organized by Alcoholics Anonymous in 1935. Their

purpose was to assist individuals with substance use disorders in their endeavor to become abstinent and remain sober (Baldacchino & Baldacchino, 2009). In the 1960s, the civil rights movement raised awareness toward people's collective power. This sparked the formation of new self-help groups that were focused not only on recovering alcoholics but also on different kinds of challenges, including mental health problems. A decade later, the emphasis shifted from mass movements to small group movements, which fueled the foundation of self-help groups further (Vattano, 1972). International networks emerged in the 1980s, and in 1994, Lavoie, Borkman, and Gidron (1994) published their seminal book *Self-Help and Mutual Aid Groups* (Oka & Borkman, 2000). In recent decades, such coalitions have spread on a large scale. Up to 20% of all people living in the United States have been part of a self-help group at one point in their lives (Kessler, Mickelson & Zhao, 1997).

While self-help groups seem to be suitable and fitting to support college students with dyslexia, a systematic search of the databases Academic Search Ultimate, Education Full Text, Education Source, ERIC, LearnTechLib, and PsycINFO (conducted on August 31, 2022, using the algorithm “dyslexia” AND [“self-help group” OR “self-support group”] AND [“university” OR “college” OR “higher education”]) did not yield a single hit. This topic is clearly not on the radar of the scholarly community. In their paper “Group development in self-help groups for college students,” Fuehrer and Keys (1988) pointed out that “the autonomy of mutual-aid groups from mental health professionals has severely limited the opportunity for scientific study of the development and functioning of these groups” (p. 326). However, this explanation is not too convincing today. Self-help groups for university students are well established by now. They focus on how to cope with eating disorders, childhood abuse, physical handicaps, cancer, drug addiction, sexual assault, and several other challenges. Many of these endeavors have been thoroughly evaluated (e.g., Burnette & Mazzeo, 2020; Fu & Cheng, 2017; Gary & Remolino, 2000; Greenbaum, 2018; Meissen, Warren & Kendall, 1996).

One reason self-help groups for college students with dyslexia have not yet become common might be the potential backlash when others realize that their reading and/or writing skills are considerably below average. Most of them have experienced a lack of understanding of their struggles or even flat-out discrimination, harassment, or ostracism by their peers and teachers. Many university programs are highly competitive. It is difficult to reveal any kind of study-related weakness in a “survival of the fittest” environment. Having a physical illness might be incriminatory, but it does not make someone look incompetent. With reading and writing problems, the situation is different. College students with dyslexia often fear that their instructors will not consider them fit to pursue academic studies once they realize that these students have trouble with basic lit-

eracy skills. Their peers might look down on them and not take them seriously. Hence, many of them are too hesitant to entrust anyone at their institution with their condition and avoid revealing them at all costs (Yip, 2018).

DIGITAL SELF-SUPPORT GROUPS AS A PROMISING OPTION TO MEET THE SPECIFIC NEEDS OF COLLEGE STUDENTS WITH DYSLEXIA

A self-evident solution to this dilemma is a self-help group setting that facilitates more anonymity. Staying incognito is significantly easier when meeting online instead of in person. Participants can even choose to attend online meetings under anonymous usernames and meet with students from remote institutions. Some common ways of connecting with others include live video conferences, chatrooms, bulletin boards, social media apps, and internet forums. To create a feeling of solidarity and combat loneliness, communicating in real time and being able to actually talk with others is oftentimes more conducive than, for instance, posting some information or reading about someone else's experience. Thus, video conferencing should play a central role in self-help groups. It enables the participants to have live conversations in different locations using a phone, tablet, laptop, or desktop computer. Online self-help groups have not become a widespread phenomenon until recently. Nonetheless, since the beginning of the COVID-19 crisis, people have become more used to meeting through video conferencing and exchanging information through the internet. Research indicates that digital self-help groups can be (at least) as effective as in-person gatherings (Kramer, Conijn, Oijevaar & Riper, 2014; Riper, Spek, Boon, Conijn, Kramer, Martin-Abello & Smit, 2011).

Of course, online self-support networks have their downsides. In a video conference, a lot of verbal and nonverbal cues (body language, eye contact, posture, physical distance, etc.) are lost. Leaning forward and making eye contact usually indicates interest, while leaning backward and looking away is typically a sign of indifference. In a video call, all the participants see is one another's faces and shoulders, and while we are looking at someone on the screen, that person sees us staring at a random spot. This skewed visuality creates emotional distance and makes it, at times, almost impossible to interpret someone's nonverbal behavior adequately (Kaiser, Henry & Eyjólfsdóttir, 2022). In addition, the online format hampers the possibilities to intervene in the case of an emotional crisis. If the group members notice a moment of extreme mental vulnerability, it is extremely difficult to connect with the person in distress. For this person, it is impossible to experience the empathy of somebody's body language, eye contact, or touch on the shoulder (Ierardi, Bottini & Crugnola, 2022). Moreover, if some of the interaction happens in written form, individuals with problems in literary language (such as college students with dyslexia) are limited in their chances to participate (Gary & Remolino, 2000).

However, despite these cons, the pros still apparently outweigh the drawbacks by far. Apart from the benefit of enabling participants to maintain their privacy, online self-help groups for college students with dyslexia offer notably three substantial upsides (Drebing, 2016; Gary & Remolino, 2000):

1. Easy access. Online self-help groups are available to anyone at any time. As long as someone is connected to the internet, she or he can participate. Such easy access makes it much more likely for university students with dyslexia to join a group than if they had to resort to visiting a certain location in person.
2. High specialization. Not everyone with severe difficulties in reading and writing is the same. Depending on someone's peculiar life circumstances, personality traits, behavior patterns, and many other characteristics, she or he might feel safer and more comfortable with some people than with others. Because physical distance is irrelevant when forming online self-help groups, it is possible to create clusters of students that constitute a "perfect" match.
3. Adaptable frequency. The amount of support that a certain individual needs might vary over time. In a crisis, someone can receive additional help by taking part in more than one network without having to travel to a place where she or he can find the next group.

As mentioned above, relevant professional databases do not yet contain any scholarly publications on the topic of online self-support groups for students with dyslexia. Hence, we do not have any empirical findings available on what works best with such kinds of assistance networks. There are no specific study results that could guide the decision-making process when trying to define the essential characteristics of a potentially beneficial self-help group. However, referring to the textbook by Drebing (2016), we can formulate five different alternatives that should be considered and then decided on:

1. Online support groups for students with dyslexia can be completely unguided, with all attendees participating because of their status as peers, or can have facilitators who offer structure and manage the frame conditions.
2. They can be open to drop-in attendance or be organized as closed groups, with attendance limited to a specific set of members.
3. They can be limited or unlimited in size.
4. They can have a set routine or be unstructured.
5. They can limit the length of participation (allowing members to only attend a specific number of meetings) or can be open in this respect.
6. They can be chartered and run completely autonomously by students with dyslexia or be associated with some charitable organiza-

tion, health-care provider, or nonprofit association.

In the following, we provide a rationale for why, from each of these six juxtapositions, one particular option should be chosen over the other when setting up self-support groups for university students with dyslexia:

Appointing a facilitator. Being a facilitator of a self-help group does not mean being in charge. After all, the collective is always responsible for what happens. However, at least one person should take care of initiating an exchange among members about how to set up a basic framework for working together, organizing meetings, distributing invitations, creating a comfortable setting, sparking conversations, and so on. This must all be done in a nondirective fashion (Drebing, 2016). Probably the largest secondary analysis on digital mental health treatments, conducted by Garrido et al. (2019), suggests that online interventions are most effective if they are supervised. This calls for choosing someone who functions as a facilitator as opposed to having a completely unguided group. What is important when doing so is ensuring that this person is up for the job. While they must never take on the role of a therapist, facilitators need to know how to react when members experience emotional disturbance during a session. Moreover, they need to be capable of moderating a meeting without talking too much while always being mindful of key moments that require a special response. All this requires ample preparation, preferably by a trained clinician or counselor during several in-service sessions (Drebing, 2016).

Organizing a closed group. As indicated above, the fear of getting “caught” or dismantled as someone unable to read or write properly is a constant companion of most college students with dyslexia (Abbott-Jones, 2021). This makes it especially important to provide a safe space for the attendees of a self-help group. As Gary and Remolino (2000) pointed out, individuals with unscrupulous motives can deceive members of online meetings. The vulnerable group of university students with dyslexia should be protected against such threats. Thus, spontaneous drop-in attendance does not seem appropriate. Instead, taking part in an online self-support group for college students with dyslexia should be strictly limited to certain members. It should thus have a trustworthy person who manages the registrations and all membership administrations. She or he knows some of the members’ personal information (e.g., name, address, phone number) but keeps it confidential. This individual should not actually be part of a group but function as its gatekeeper, ensuring that no one who poses as a menace (e.g., a staff member of an associated nonprofit organization) enters. This way, everybody can maintain their anonymity if they want and feel secure.

Limiting the size. Bloom, Mizen, and Taneja (2022) reported on a survey of 2,077 employees about the ideal size of online meetings. Accordingly, while in-person gatherings of ten people or more are considered appropriate and suitable, the preferred number in digital get-togethers should not exceed four by

much. Business meetings are certainly different from those of self-help groups. However, it makes sense to set limits concerning the number of participants on any kind of online encounter where people should be granted a sufficient amount of time to share their feelings, thoughts, and experiences. To our knowledge, there are no empirical findings about the ideal size of online self-support groups. However, exceeding the acceptable number of attendees specified in the paper by Bloom et al. (2022) is inadvisable; five seems expedient. Moreover, considering that online meetings are usually more strenuous than face-to-face gatherings, the length should be limited (e.g., 60 minutes).

Having a set routine. Many college students with dyslexia have experienced bullying or even abuse (Fuller-Thomson & Hooper, 2014). While the chances of intentional, aggressive behavior against one another within a self-help group can be considered relatively small, establishing certain rules that specify a code of conduct might add to a feeling of safety. The first self-help groups, organized by Alcoholics Anonymous, imposed a particular etiquette on themselves and have kept it ever since (Bill, 2019). Other initiatives have done the same. Drebing (2016) lists a number of rules of behavior that can foster the healing atmosphere in a self-help group: “Be respectful to everyone, no personal attacks, disagreements are okay, gut respect the person” (p. 23). It is not unusual to reiterate such a code at the beginning of each meeting, along with reminding everyone of its overall purpose. Adopting such a practice for self-support groups serving university students with dyslexia seems expedient. The same goes for other rituals, such as always making time for personal check-ins (in which members give updates on how they are doing) or having the facilitator give a summary of what has been talked about at the end of a session.

Granting everyone unlimited participation. A study by Dean, Potts, and Barker (2016) indicates that online self-support groups can help address depression and anxiety as well as increase life satisfaction after six months. In accordance with this finding, an experiment by Griffiths et al. (2012) shows that such interventions are ineffective after only three months, but elicit significant improvements appear at six and twelve months. For groups centering on other topics (such as breastfeeding, debt, or eating disorders), this might be different. However, because university students with dyslexia struggle mostly with internalizing symptoms, it seems appropriate to plan for digital self-help groups that operate for no less than half a year. Thus, members should be allowed to participate for a relatively long period without setting a limit on the maximum number of meetings.

Connecting with other suitable organizations. Drebing (2016) rightly pointed out, “Peer support groups are natural partners to formal care providers” (p. 61). In Germany, for instance, health insurance companies invest a certain percentage of their revenue to promote and maintain such initiatives. As

outlined above, many institutions of higher education run their own disability services. They often cooperate with different professional organizations, such as the International Dyslexia Association, Dyslexia Canada, or the Centre of Excellence for Dyslexia. Members of self-support groups for college students with learning disabilities in the areas of reading and/or writing are well advised to make use of the opportunities that these allies can offer. Such networks can certainly contribute to providing members with a lot more assistance, aid, and useful information on how to best cope with dyslexia in a higher education environment than if they had to depend entirely on a couple of their peers.

CONCLUSION

It is astonishing that a considerable number of college students suffer from serious problems in literary language or even dyslexia, but the literature on this topic is unusually scarce. Our society wastes an enormous amount of potential by not sufficiently supporting this population and risking them dropping out of their education programs. We need to concern ourselves more with this group and try harder as we struggle to determine how to best support them. Surely, numerous disability services at different colleges do an excellent job in this respect, but this is, by far, not the case everywhere. In addition, more than a competent disabilities service center is needed to attend to the most crucial needs of an afflicted individual. Self-help groups could certainly add a vital ingredient to a success formula that helps college students with dyslexia carry on. These students frequently experience loneliness and feelings of isolation, and self-support groups could remedy their suffering. In this paper, we attempted to shed more light on the whole issue of dyslexia in higher education. In addition, we argued for certain features that should be considered when setting up a self-help group. However, we lack empirical data to substantiate the validity of our suggestions. Solid research is needed to fathom the impact of online self-support groups on the well-being and mental health of college students with dyslexia. This group deserves more attention not solely because of ethical reasons but also because as a society, we cannot afford to lose them on the way and waste their potential.

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