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Editorial

Who Has the Right to Say What the Body Means?

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Who has the right to say what the body means? This is one of the questions those concerned with the power of media – and of access to media – frequently consider. The multiple forms of media (traditional and new) that we experience can have a profound influence on how we consider the body. Those myriad voices frequently dictate (or try to dictate) what we as communities believe it means to be beautiful, what it means to be a man, what it means to be a woman, what it means to be “normal,” even what it means to be human. Increasingly democratic possibilities of new media and media distribution have given forum to many new voices to give their own take on these questions. There have increasingly been more ways to expand and interrogate sacred notions of the body, whether the sacred cultural scripts of gender, race, or those of what it means to have a disability.

Many of these voices--like Liz Crow (<http://www.roaring-girl.com/>), Mat Fraser (<http://matfraser.co.uk/>), or the work of Art of the Lived Experience (http://www.mlive.com/onthetown/index.ssf/2015/03/defined_by_art_international_e.html) and many others, in film, in performance, in music, and other media forms take up the task of challenging dominant notions of what the body means and who gets to have a say. These voices frequently tell their own stories, invite audiences to share and question their own, and--sometimes directly, sometimes indirectly--invite us to imagine new stories yet untold, yet un-lived, about what the body can mean, what a true community can be, free of labels, free of the nervous politics of borders that anxiously medicate, discriminate and attempt to order the delicate, indescribable beauty and pain of being who we are.

For those of you reading this now who may have visual, audio and other multimedia work that engage these important questions, you are invited to submit work to the *Review of Disability Studies* to continue the conversation with an international audience made up of scholars, laypeople and other interested people. Works may include digital film, sound files, or artist statements, or other experimental forms. Special attention will be given to those works that give unique, embodied exploration/interrogation of the contradictions of what disability is/is not, and fiercely claim their own right to decide the answer.

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Research Articles

“We Are Authors”: A Qualitative Analysis of Deaf Students’ Writing During One Year of Strategic and Interactive Writing Instruction (SIWI)

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Abstract: This article expands on prior Strategic and Interactive Writing Instruction (SIWI) research by examining students' development as writers. Findings from a qualitative analysis of the writing development of 20 middle-school deaf and hard of hearing students over one year of instruction is reported. Implications and future directions are discussed.

Key Words: writing, deaf/hard of hearing, engagement

Introduction

Even though efforts to establish the notion of Deaf Culture and a socially empowered Deaf Community have been well documented (Moore & Levitan, 2003; Padden & Humphries, 1990, 2005), research and policy related to education for the deaf and hard of hearing (d/hh) have historically focused on deficits and difficulties. For decades, federal policies related to education for the deaf made no mention of the unique language and cultural needs of d/hh students. Thus, policies meant to increase inclusion actually limited language and identity resources for d/hh students by privileging English-only, hearing-centered approaches for interaction and development (Rosen, 2006).

Similar to the ways in which federal education policy does not assume valuable deaf ways of being and learning, research narrowly characterizes the literacy experience of the deaf with terms like “plateau”, “struggle”, and “persistent low achievement” (Antia, Reed, & Kreimeyer, 2005; McAnally, Rose, & Quigley, 1994; Moores & Miller, 2001; Yoshinaga-Itano, Snyder & Mayberry, 1996). These terms are most often associated with standardized assessments, which compare d/hh students to their hearing counterparts, the normative population. One of most pressing topics of concern within the field of deaf education is the pattern of little progress in reading achievement for d/hh students in middle and high school (Gallaudet Research Institute, 2003; Yoshinaga-Itano & Downey, 1996). Due to their unique developmental histories, which often include language delays in the primary expressive/receptive language, d/hh students exhibit challenges in learning to write effectively and fluently (Dostal,

Bowers, Wolbers, & Gabriel, 2010). While we know d/hh individuals have academic struggles, there is a dearth of information about successes and strengths in the research literature.

One promising writing intervention designed for the unique needs of d/hh students is Strategic and Interactive Writing Instruction (SIWI). SIWI, the instructional approach used in this study, has significantly impacted students' writing skills at the word-, sentence-, and discourse-level (Dostal & Wolbers, 2014; Dostal, Wolbers, & Bowers, 2012; Wolbers, 2008, 2010). The success demonstrated by the students that participated in SIWI run counter to the dominant narratives of literacy failure that are told and retold in the existing literature on literacy and deafness. In this article, we present a set of findings from a larger mixed-methods case study designed to deepen our understanding of students' development as writers working between two or more languages. The research question that guided the inquiry described in this article was: How do students who are d/hh develop as writers over a year of SIWI?

Background

Though the literature on literacy instruction for d/hh students provides few examples of successful writing interventions, there is a growing research base that supports the use of SIWI (Dostal & Wolbers, 2014; Dostal, Wolbers, & Bowers, 2012; Wolbers, 2008, 2010). In an effort to deepen our understanding of these trends, we collected both quantitative and qualitative data across the school year in the first author's middle school classroom, drawing upon evidence from student writing samples, classroom artifacts and observations, as well as teacher reflections and student interviews to deepen our understanding of d/hh middle school student's development as writers.

Quantitative analyses of the intervention in this study on word- and sentence-level writing skills have been reported in (Wolbers, Dostal, & Bowers, 2012). The quantitative component of this mixed methods study demonstrated that students of all levels of language proficiency, and a range of linguistic backgrounds, made significant progress on written expression during the year of instruction. In other words, SIWI was effective regardless of participants' language histories and methods of communication. Moreover, by always beginning with each writer's preferred method of communication, regardless of proficiency, SIWI values students' choices, needs, and differences. Similarly, Dostal's 2014 study compared student progress across 5-weeks of regular writing instruction with progress after a 5-week SIWI intervention, and found that the trend of little progress was evident among middle grades students receiving regular instruction, but students demonstrated significant gains in communicative proficiency after only five weeks of exposure to SIWI. In a study of 3 classes in the middle grades (Wolbers, 2008), this pattern of success was also demonstrated in the development of word-, sentence, and discourse-level writing skills.

Table 1
Driving Principles of SIWI with Definitions

<u>Principle</u>	<u>Definition</u>
Strategic	The instruction is strategic in the sense that students are explicitly taught to follow the processes of expert writers through the use of word or symbol procedural facilitators.
Interactive	SIWI is interactive in the sense that students and the teacher share ideas, build on each other's contributions, and cooperatively determine writing actions. Through this process, the student externalizes his/her thoughts in a way that is accessible to his/her peers.
Linguistic and Metalinguistic	Persons have two separate routes to develop ability in a second language—acquiring implicitly and learning explicitly. The implicit and explicit approaches of SIWI aid in developing linguistic competence and metalinguistic knowledge among d/hh students (Dostal, Bowers, Wolbers, & Gabriel, 2012).
Balanced	While writing as a group, the teacher identifies balanced literacy objectives for his/her students that are slightly beyond what students can do independently. The teacher is cognizant to target a mixture of word-, sentence-, and discourse-level writing skills that will be emphasized during group guided writing.
Guided to Independent	When the teacher has the ability to step back and transfer control over the discourse-level objectives (e.g., text structure demands) to the students during guided writing, s/he will then move students into paired writing. The teacher will circulate the room to observe what students can do in a less-supported environment. If students exhibit good control over the objectives, the teacher then moves students into independent writing.
Visual Scaffolds	Showing promise in supporting the learning of d/hh students (Fung, Chow, & McBride-Chang, 2005), visual scaffolds offer another mode of accessing the knowledge of more-knowledgeable-others. In SIWI, students use visual scaffolds to recognize and apply new writing strategies or skills they are in the process of learning.
Authentic	During SIWI, the students and the teacher generate, revise, and publish pieces of text for a predetermined and authentic audience. Writing instruction and practice is always embedded within purposeful and meaningful writing activity.

Strategic and Interactive Writing Instruction (SIWI)

SIWI is comprised of seven driving principles (see Table 1), with three overarching, theoretical-based principles. Strategy instruction (1) is rooted in cognitive theories of composing (Applebee, 2000; Flower & Hayes, 1980; Scardamalia & Bereiter, 1986), interactive instruction (2) in sociocultural theories of teaching and learning (Bruner, 1996; Lave & Wenger, 1991; Vygotsky, 1978, 1994; Wertsch, 1991) and metalinguistic knowledge and linguistic competence (3) in L2 theories (Bialystok, 2001; Ellis & Laporte, 1997; Krashen, 1994).

SIWI involves explicitly teaching the processes of expert writers through strategy instruction (Graham, 2006; Applebee, 2000) as well as the use of procedural facilitators such as visual scaffolds and mnemonic devices for structures and conventions of composition. SIWI also positions students as learners within an apprenticeship model, with the teacher as an expert writer who gradually transfers responsibility for writing as students appropriate modeled skills and strategies (Englert & Dunsmore, 2002; Englert, Mariage & Dunsmore, 2006; Mariage, 2001). Finally, SIWI supports explicit language learning by drawing comparisons between students' initial ideas (in whichever form or language they are first expressed) and the written English representation of those ideas. In this way, SIWI honors all variations of language histories and proficiencies that students bring to the lesson, and uses the translation of initial ideas into written English as an opportunity to develop metalinguistic awareness. The goal of developing metalinguistic awareness for all languages used in the classroom, rather than honoring one language above others, sets SIWI apart from other interventions or instructional approaches for the d/hh aimed at development of English only. This leads to active involvement for all participants, regardless of language background. SIWI also supports implicit language acquisition of English and linguistic competence through frequent rereading of English text (Wolbers, 2010) (See Table 1 for more detail on SIWI).

Methodological Approach

The data presented in this study come from a larger mixed methods analysis that combines both qualitative and quantitative approaches (Johnson, Onwuegbuzie & Turner, 2007), of a single case of intervention. Though we present only the qualitative findings in this paper, we do so in an effort to draw attention to “multiple ways of seeing and hearing, multiple ways of making sense of the social world” under investigation in our research (Greene, 2007, p. 20). As Flyvbjerg (2011) has noted, case studies can offer the depth of understanding of context and process, which complements the breadth of statistical methods. Given the overarching deficit-focused narrative constructed by existing research on deafness and literacy, we were committed to presenting a counter story that illustrates alternatives and inspires a new focus on possibilities for teachers and researchers - one that values linguistic diversity and leads to empowerment and development.

Participants and Setting

The case is bound by one classroom of 29 students led by one teacher, spread across five class sections and three grade levels (two sections of 6th grade, one section of 7th grade and two sections of 8th grade). The teacher explained to the students that both teacher and student would track their writing growth and perceptions of writing throughout the school year. Students had a mean age of 13.2 years, a mean SAT-HI reading comprehension score of 2.7, and ranged from having mild to profound hearing loss (mean loss of 88dB). Students varied in their expressive language communication (e.g., speech, American Sign Language (ASL), English-based sign, or delayed in both ASL and English) and varied in the amount of exposure to ASL they received at home, from deaf adults at school, during student conversations, and during residential hours.

The teacher was a full-time instructor in a residential school for the deaf. In addition to an MS in Education, she has a BS in Educational Interpreting and a rating of Advanced Plus to Superior Plus on the Sign Language Proficiency Interview. After teaching for four years and being trained to deliver SIWI the semester prior, she used SIWI in place of regular Language Arts instruction for 45 minutes per day with each of her five classes throughout the entire school year. The teacher was regularly observed in person and via video recordings in order to maintain an ongoing record of fidelity of implementation (average 3.7-4.0 on a 4.0 scale) and a written record of observations and feedback.

Data Collection

Teacher/Researcher's Field Notes and Reflections

The teacher kept a daily log of activities and observations as well as a journal for reflections throughout the year. The activity log and reflection journal included a daily account of how class time was used, which objectives were taught, and written observations, notes and reflections for each of the five daily class periods. Researcher field notes from monthly observations were compiled with the teacher's activity log.

Student Interviews

At the end of the year, each student participated in a brief (10-15 minutes), videotaped interview with the teacher. The interview protocol (see appendix A) involved showing the individual student examples of their writing from the beginning, middle and end of the year, then asking them to describe and reflect upon what they noticed.

Artifacts of Student Work

Copies of student writing were also used as data in this analysis. Both official pre-, mid- and post-intervention writing samples as well as copies of drafts, works in progress, and notes between students and the teacher were scanned/copied as artifacts of student work.

Videotapes of Classroom Instruction

Each of the five classes were videotaped approximately once every two weeks. These videotapes were analyzed and coded for examples of various aspects of SIWI and as triangulation for patterns noted in the researcher's daily log and reflection journal. The SIWI Observation and Fidelity Instrument (Appendix B) was used to code and tag videos as examples of various aspects of SIWI to be considered along with patterns in the researcher's daily log and reflection journal.

Analytic Approach

In order to answer the question, "How did students develop as writers during SIWI?" we conducted a thematic analysis (Saldana, 2012), beginning at the level of micro-patterns and codes across sets of data in terms of students' uses of writing within and outside of class, and moving to abstract patterns that related to development of writers. As we read and re-read field notes, reflections, student writing, and watched videos of classroom instruction, we pulled out examples and scenarios that addressed these three linked analytic questions: "How are students engaging in writing, or how are they using it?", "What are students writing about?", and "How are students talking about their writing?" These linked questions allowed us to focus our attention on students' development as writers by identifying elements of authors' craft such as topic, purpose, and audience.

Extraction and categorization of unexpected and notable themes was conducted independently by all authors. Seven themes were initially identified: awareness of writing ability, interaction with visuals, increase in desirable behaviors, communication skills, initiative to engage in writing awareness of self as author and coping with loss. A consensus among researchers was reached and these themes were consolidated into four patterns, which included development in: 1) initiative to engage in writing, 2) purpose for writing, 3) awareness of writing ability, and 4) independence as writers.

By looking for examples that addressed each of the analytic questions over time, we were able to identify several patterns in students' development as writers. We then looked across data sets for examples and non-examples of each pattern.

Findings

In the following section, we describe each of the four patterns produced from our analysis of data sources collected across the intervention. Each pattern is illustrated by representative excerpts from the teacher's reflective journal in order to provide examples. These excerpts may include direct quotations from students (all names are pseudonyms) and their compositions (represented in italics). Before including each excerpt, the teacher shared them with her students, sometimes co-constructing revisions of the excerpts with the students, in order to include students' perspectives within her reflections on their writing activity. The patterns include development in: 1) initiative to engage in writing, 2) purpose for writing, 3) awareness of writing ability, and 4) independence as writers.

Initiative to Engage in Writing

Across each of the data sets, we identified patterns in students' individual initiative to engage in the writing process. For example, by November (the fourth month of intervention), daily notes from the teacher's log showed that students across classes had begun to ask for more independent and guided writing time in class, though there are no instances of such requests before this time in the year. This stands in direct contrast to the teacher's experiences prior to SIWI as well as the existing literature on d/hh students' interest and desire for writing. For example, Albertini (1993) noted in his study of both American and German deaf students that, "The majority of statements in both samples indicated that the students did not like to write. The process was described as 'difficult' and the products as 'bad' or 'needing improvement'" (1993, p. 68). Yet, after only months of participating in SIWI, students independently initiated or requested opportunities to write.

In addition, classroom videos show several instances in which students spontaneously shared that they had begun a story or continued a class writing assignment outside the classroom, and were eager to share what they had written. This willingness to share does not necessarily demonstrate confidence in their writing, but indicates an understanding and desire to communicate with others through writing. Through SIWI, writing with real purpose and sharing with an authentic audience are always integral to the process.

In order to further illustrate the students' increased willingness to write and willingness to share, we present the following excerpt as one of many examples of this pattern. Statements in quotations are direct quotations from students (sometimes translated from ASL to English) from classroom videos, interviews or teacher field notes. In cases where they are not verbatim quotations, they represent the teacher's interpretation, and have been shared with, and at times edited by, the students themselves:

“Today, one of my students, Maya, came into class and said, ‘This weekend I was interviewed by the local radio station because I wrote Regal cinemas and President Obama a persuasive letter like the writing we’ve been doing in class. Let me pull it up on the internet and show you.’ She pulled up the interview with the radio talk show host and it showed a video of her explaining the reasons that movie theaters should caption new release movies for d/hh people (see Figure 1). Along with her video, there was a copy of the letter she wrote as well as one her mother sent to add her support. Ten or so readers had already posted online responses, both in support of Maya and in defense of the movie theater. She wrote back to each of them, explaining her reasons and refuting counterarguments.



Figure 1. *Picture of Maya at the radio station.*

Her original letter explained that when she goes to the movies with her family, they all laugh, but she has no idea why. She wanted captions to be able to laugh with her family.

Mr. President I am writing this letter because on the weekend and during the summer break I [like] being with my friends and family. And one of the things I really like to do is attend movies, but I do not go as much as I would like to go. The reason I do not go is because there are no Captions of the screens, so I do not enjoy the movie. I see other people laughing or crying [and] my mom has to tell me what is being said but by the time we both finishing discussing it, I have missed the next part.

Maya wrote for a real purpose, using all the elements of persuasive writing that were introduced in class through SIWI for something she cared about. For example, she acknowledged the cons of captioning - that it might not be cost effective or may be distracting to some viewers. Maya addressed each issue in her writing.

I told my mom that I wish there were a way to add captioning into the movies, at least in one room have them playing. I realize it could be very expensive to have captions in every room and people may not like words on the screen.

Before we began class Maya went on to describe her next project: ‘Now I have to write a letter to the radio station.’ She pointed out that the radio station did not caption the video that was posted online, and therefore it was not accessible to deaf and hard of hearing individuals, the very persons with a vested interest in this issue. Maya made the connection that writing was a way to communicate to a real audience, and turned writing into a way to voice her thoughts. She represented herself through writing as an active, and contributing citizen in her community, with something to add to public discourse about disability and difference.”

Though we do not have evidence that increased initiative to write is a direct result of any designed features of SIWI, we can hypothesize how SIWI may have contributed to this development. For example, SIWI is designed to leverage intrinsic motivation by valuing students' linguistic choices and differences, providing support in the form of guided instruction, requiring all writing assignments to have a stated purpose, and allowing students to choose the topic and audience for their composition. In other words, choice, authentic writing, and guided instruction are considered driving principles of the SIWI approach (see Table 1). We use the term authentic to describe any piece of writing that is written to a real (rather than contrived) audience and delivered to that audience. For example, a letter that is written to the principal and delivered to the principal for comment would be considered authentic. The opposite, a contrived writing assignment, would be a five-paragraph essay that does not have a specific intended audience, is read only by the teacher, and is composed solely as an educational exercise rather than as purposeful communication.

A range of theories of motivation (e.g., Expectancy Theory, Vroom, 1964; Self-Determination Theory, Deci & Ryan, 1985) could be used to support a hypothesized link between SIWI and intrinsic motivation because they highlight the importance of choice, purpose and support in the development of motivation for any task. Within literacy research, Guthrie and Humenick (2004) have also noted the importance of choice and authenticity in designing instruction that promotes student engagement. In this study, there is evidence that some combination of these principles was at work during the year-long intervention because students demonstrated increased initiative and willingness to write.

We also noted an increase in willingness to share writing with adults and with peers. For example, two 8th grade students reported sharing their writing with their parents. Two 7th grade students began routinely asking to stay inside from recess in order to work on the mystery stories they were co-constructing. As noted above, Maya chose to deliver her letter to the cinema, its intended audience, as well as with her peers and teacher in class. A 6th grade student wrote a story related to science that she asked to share with visiting science fair judges during the school's science fair. These are only a few of many examples of willingness to share writing within and outside of class that are found throughout the data from students across sections and grades.

This increase in willingness to share and engage in writing was accompanied by a decrease in the number of off-task behaviors we associate with avoidance or frustration. This was not an aspect of instruction we formally coded or tracked within video observations; however, both the teacher and researchers separately noted a change in the volume of off-task behaviors across the year. For example, at the beginning of the year, researcher field notes pointed out that students would quickly withdraw from an interactive writing activity if they perceived their input as wrong. The teacher's reflection journal also noted that writing time in the classroom was, at first, a time filled with frustration and behaviors such as pencil throwing and shoving papers off desks, or disengaging from signed communication by looking away or closing eyes.

In contrast, students who had once routinely packed up early to go to more favored classes (e.g., gym, lunch, etc.) demonstrated reluctance to leave their writing class as illustrated in this excerpt from the teacher's reflective journal:

“Today, when I set the timer for 15 minutes of independent writing time so that the class wasn't late for Physical Education, Dane said, ‘No! More! Last week we decided. More!’ I suppose Kasie noticed my confused expression and elaborated, ‘Last week when you were absent, we decided we need one hour to write. Dane said it would be really great if we had a few hours, but we need at least one.’ My confused expression never faded because I was thinking: these students are tracked in the lowest performing, language-delayed group, why do they want to write?”

In order to investigate why students were more willing to write, we examined examples of students' purposes for writing. The pattern we observed in answering this question is presented as our second pattern.

Purpose for Writing: Sharing Writing to Clarify Communication and Understanding

In this section we describe a pattern in students' purposes for writing. Across data sets, we found evidence that students wrote and revised with the intention of both clarifying their own understandings of experiences and ideas, and in order to increase the clarity of communication with their readers. Specifically, students often became aware of missing information and conflicts in details as they shared their writing with their peers. Rather than accepting or giving up on these limited accounts of their experiences, students seemed to be motivated to create revised and expanded versions of stories. As we looked across examples of student writing from across the year, we noted that many students crafted multiple versions of the same story or paper even though they always had free choice of what to write about.

In some ways, the pattern of writing the same stories over and over again is similar to a phenomenon related to reading in which children often like to re-read texts they like or are comfortable with multiple times (Schleper, 1995). Indeed, familiarity with a topic may have contributed to students' desire to write about it more than once. Still, this pattern is somewhat different from rereading a familiar text because new versions of the same story changed and expanded over time, usually as a result of sharing them with a parent or peer. Feedback and questions from readers prompted students to clarify their ideas and ways of communicating them.

For example, after sharing a personal narrative about his early childhood with parents over the weekend, one 8th grade student decided to write a second version of the story that incorporated details that his parents had shared when they read his first version. A 6th grade student was able to discuss details he remembered from a trip with his peers in order to clarify event details. Video recordings of a class period show the student drawing and signing about having seen a large model boat. As his peers asked clarifying questions, they helped him identify the large boat as a Titanic replica just like the one used in the movie. So, discussing what he remembered seeing with peers during shared writing allowed him to clarify his understanding and negotiate how to represent the experience in ASL and in English.

The following excerpt from the teacher's reflective journal describes another set of examples of writing to understand: one is described by a student during an end-of-the-year interview, and others are taken from conversations with students and observations of independent writing in class:

"I asked Sarah, 'How do you feel about writing?' She answered, 'It makes me feel like I understand fully what has happened in my life—what I should know, what I should remember.' Sarah's answer reminded me of the way Tristen learned more about the story of how he lost his hearing by writing what he knew and sharing it with his father. One Monday, Tristen showed me a short story that he wrote about losing his hearing, and then he handed me a piece that his father had written about the same topic. Tristen explained

that he gave his story to his father and asked his dad if he would clarify some facts— and then he and his dad wrote a new story together.

Today during class as I looked across the room, I noticed that Katie was writing a story about her volleyball victory for the third time. Sitting across the room, Andrew was rewriting his story about volunteering at the fire department with his grandfather. Another student, Erin, had laid out her two drafts about the story of her adoption and was comparing them. As I watched, she set both aside and started crafting her story again.”

These observations demonstrate the students’ desire to use writing to understand and communicate ideas and experiences more fully. Expanding on experiences through the revision of previously constructed text demonstrates an increase in the students’ awareness of how experiences can be recounted through text as well as awareness of the purposes and possibilities of the writing process.

Though we cannot attribute this pattern of using writing to clarify understandings and communication to any specific aspect of SIWI, we hypothesize that the emphasis on writing for an audience, along with opportunities to co-construct texts within shared writing experiences, may have contributed. The emphasis on writing to a specific audience positions the act of writing as inherently communicative and it affords them tools to communicate with others outside of the deaf community. In contrast, when writing to no particular audience, the focus of writing may have more to do with conventions and fulfilling a specific structure than communication. Likewise, when students have the opportunity to co-construct texts (when transitioning from modeled to guided, shared, and finally independent writing), the opportunity to negotiate meaning becomes part of the writing process. As students discuss how to transfer their signed, spoken, gestured or drawn ideas into written English, they have to negotiate the conventions of English writing as well as the intention of their words.

These opportunities to build metalinguistic awareness by negotiating meanings and comparing different ways to express an idea also seemed to contribute to a general increase in communicative competence. As reported in Dostal & Wolbers (2014) and Wolbers, Dostal, & Bowers (2012), quantitative analyses demonstrated an increase in signed and written communication proficiency for all students regardless of beginning levels of proficiency. We hypothesize that opportunities to build awareness of both English and ASL by negotiating meaning collaboratively in the writing process supported the development of both languages. Even students who were not proficient in ASL at the beginning of the study, and those who wrote English compositions of no more than a few words in length, demonstrated increased proficiency in both languages.

Awareness of Writing Ability

At the beginning of the school year, negative feelings towards writing were evident in students' comments during class: "My writing stinks." "I hate writing." "I don't write." These expressions of negative feelings are echoed by a broader trend reported in research on d/hh students in which attitudes toward writing in general and evaluations of one's own writing were generally negative (e.g., Albertini, 1993).

Guided instruction—in which writing is modeled and then gradually released to the group for shared writing and to the individual for independent writing—is one of the driving principles of SIWI. This guided approach is designed to increase student's competence and confidence by allowing them to observe and discuss strategies for composing texts. After several months of SIWI, students' comments in class and within student interviews demonstrated that they were aware of strengths, weaknesses, and growth as writers. Furthermore, students began to identify as authors/writers in their conversations with the teacher and in end-of-the-year interviews.

In one end-of-the-year interview, a 6th grade student explained that her writing "stunk before sixth grade." She pushed the writing sample that she created at the beginning of the year to the edge of the table away from her saying, "It wasn't very well written." Another sixth grader explained: "It was tough when I entered middle school, we didn't know how to write, but now that we know what authors do. We are authors."

The following excerpt from the teacher's reflective journal provides another example, among many, of this pattern of increased awareness of ability and self-identification as writer/author:

"Today, Jamal asked to attend his Individualized Education Plan (IEP) meeting. He told me that during this meeting his yearly progress would be reviewed and he wanted to be there to persuade the principals and his future teachers to allow him to take an advanced freshman English class. I agreed he should go. Before we left the classroom, he asked if he could have his writing portfolio to support his request and document his progress. At the meeting he showed the faculty his writing and explained, 'I know that my writing isn't perfect and I have a lot to learn, but look at the progress I've made in less than a year. Last month I started using articles more. In February I consistently had an introduction paragraph. Now I almost always use an outline to make sure my paper has structure.'"

More than an increase in confidence, the comments described above illustrate increasing awareness of self as a writer through a reconstruction of the student's self-identity and attitude. Jamal not only demonstrated pride in his work, but an explicit awareness of the strategies and habits he has formed to support successful writing. Moreover, rather than thinking of his writing

as “bad” or “good” based on the grade it receives, Jamal described growth across the year in terms of his writing process (using introductory paragraphs and outlines) and knowing “what authors do.”

We hypothesize that the emphasis on sharing writing with peers and with an intended audience has supported students’ development of a sense of ownership over their writing and their process as writers. The emphasis on choice and authenticity ensures that students do not write in order to fill out a checklist of skills that are only relevant in class. Rather, they write to communicate their ideas to specific audiences and are aware of the successes and difficulties that arise within such communication. We also hypothesize that the supportive collaborative environment of SIWI that actively engages students in the process of rereading, questioning problem solving and revising helps them to develop evaluative skills of written text, and that all writers are continually growing in their abilities as they get more experience and practice.

Independence as Writers

This increase in awareness of “what authors do,” and students’ sense of themselves as authors were also evident in the ways students worked to maintain their independence as writers. Within SIWI, guided instruction is meant to lead to independent writing practice and independence as a writer. One way authors maintain their independence is by developing strategies that help them organize their writing and maintain structures associated with their chosen genres. Since the 29 students represented a range of proficiency in English, it was not always efficient or effective to provide written reminders of the rules or patterns associated with each type of writing. Instead, the teacher and students created “visual scaffolds” (Fung, Chow, & McBride-Chang, 2005; Dostal, Bowers, Wolbers, & Gabriel, 2008) which were supportive of deaf writers and served as reminders for students who were still learning about the structure and conventions of writing in English.

Though visual scaffolds in the form of posters or manipulatives had previously existed in the language arts classroom and across classrooms in the school, we noted video evidence that students were increasingly using and creating their own visual scaffolds to use during writing without any prompting from the teacher. We interpret this trend as evidence students were developing strategies to sustain their independence as writers. The following two extracts from the teacher’s reflective journal illustrate this pattern:

“Today, I noticed Krista sitting and facing the bulletin board during independent writing time. After asking her if she needed help, she explained, ‘I want to compare my writing with the hamburger.’ In our class, we had constructed a hamburger visual that represented the parts of a paragraph several weeks before. Without a recent reminder,

Katy was also using this visual as a reminder of the structure she wanted to create for this piece.

Today, Riko told me about a story he is planning that mirrors the surprise ending of Frank Stockton's short story *The Lady or the Tiger*. As he looked at his notes, he said, 'These [notes] are a mess, I don't even have a climax.' Seemingly lost in thought, Riko walked away. He came back to me right before the bell rang to show me the visual representation of plot he had created, and then asked if we could talk about the surprise ending now that had organized his thoughts."

Each of the two short excerpts above capture some of the many instances in which students used or created visual representations as scaffolds for organizing and composing texts in a given genre. The use of these scaffolds allowed students to maintain their independence at different stages of the writing process, and to analyze their own work and notice for themselves what might be missing from their compositions. This student action of using existing or created visual scaffolds for text structure became increasingly common across the year as students developed into independent, purposeful, and engaged writers.

Table 2

Patterns Identified through Thematic Analysis

<u>Pattern</u>	<u>Observations and Illustrations</u>	<u>Possible Contributing Factors of SIWI</u>
Initiative to Engage in Writing	<ul style="list-style-type: none"> • Students requested more opportunities to write • Students engaged in writing outside of the class • Students shared their writing • Decrease in student disengagement and off-task behaviors 	<ul style="list-style-type: none"> • Leverages intrinsic motivation through authentic writing experiences that incorporate choice and purpose • Incorporates frequent opportunities to write in a guided environment
Purpose for Writing: Sharing writing to clarify communication and understanding	<ul style="list-style-type: none"> • Students noted missing information and conflicts in details as they shared their writing • Students choose to revise and expand their original drafts • Students responded to peer and adult feedback on their writing • Students provided peers with feedback focused on clarity of 	<ul style="list-style-type: none"> • Attends to an authentic audience and the role of the writer in communicating with the intended audience • Supports the development of communicative competence by providing opportunities to collaboratively negotiate meaning with others during the co-construction of text

	ideas	
Awareness of Writing Ability	<ul style="list-style-type: none"> • Students noted their strengths, weaknesses, and growth as writers • Students identified as authors/writers during conversations with the teacher and during the end-of-the-year interviews 	<ul style="list-style-type: none"> • Emphasis on sharing writing with peers and intended audiences to develop ownership over their process as writers • Supports effectively communicating ideas to a specific audience while considering the successes and difficulties that arise during communication
Independence as Writers	<ul style="list-style-type: none"> • Students created their own visual scaffolds to use as a support during the writing process • Students independently used teacher-introduced visual scaffolds while constructing text 	<ul style="list-style-type: none"> • Focuses on developing students as independent writers • Incorporates visual scaffolds to support students as they construct text

Conclusion

In contrast to research that has focused on ways to "fix"—support and build writing skills—we have sought to document how d/hh students *are* writers, and the ways in which they continue to develop as such. In this article we have described four patterns in the development of d/hh students as writers. These patterns included changes in initiative to engage in writing, purpose for writing, awareness of writing ability, and independence as writers (see Table 2). Patterns were noted across data sets, including the videos of classroom instruction, student writing samples, student interviews, and the teacher’s daily log and reflection journal. Taken together, we interpret these patterns as evidence that the students are developing independence, purpose and engagement as writers, which empowers them to be effective communicators within and outside of their communities. In addition, we take these patterns as strong evidence of the possibility for a pedagogy of hope and confidence (Jackson, 2011) to replace the deficit discourses that too often characterize research in deaf education and on the education of students with disabilities in general. In this way, by developing American Sign Language, a cornerstone of Deaf Culture, SIWI is able to address a goal of Disability Studies: the reframing of the very notion of disability as static and internal. When instructional interactions changed to support language development in the service of literacy learning, deficits were minimized and replaced by evidence of potential.

We hope the illustrations of these patterns in varied formats support teachers and researchers in imagining alternatives, and thereby envisioning hopeful futures for students who have too often been presumed incompetent. Though we do not claim a causal link between SIWI and any of the four patterns, throughout the paper we have hypothesized how SIWI's driving principles may have contributed to these promising trends in students' development identified through quantitative analysis of growth in students' written expression.

Given the power of teachers' beliefs about student potential to influence instructional decisions and student outcomes (e.g., Scharlach, 2008), the included illustrations of each described pattern aim to provide strong evidence of a counter-narrative to the dominant stories of plateau and difficulty.

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Appendix A

List of student interview questions.

1. What do you notice about this sample?
 - a. What do you think about your writing from the beginning of the year?
2. What helps you learn to write?
3. What does not help you learn to write?
4. Do you enjoy writing with your class?
 - a. Why or why not?
5. Do you enjoy writing on your own?
 - a. If yes, what?
6. What do good writers do before they begin to write?
7. What do good writers do while they are writing?
8. What do good writers do when they are done writing?
9. What is the difference between good writers and excellent writers?

The Discourse on Autism

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Abstract: The notion that autism is fundamentally a neurobiological impairment that can be treated, cured or overcome through strategies that enable successful social adaptation is becoming imbedded in popular narratives of autism, such as the life story of Temple Grandin as recounted by Oliver Sacks. This notion compromises the autonomy and flourishing of autistic persons by placing the adaptive burden largely upon autistic persons rather than institutions. Drawing on the work of Ian Hacking and Michel Foucault, I argue that we should give this popular conception an axial shift and consider the ways in which our contemporary institutions, practices and assumptions about normality are implicated in the creation of autism as a diagnostic category and the confinement of autistic persons within the inflexible norms of extant educational and public welfare practices. Understanding the social and cultural contingency of autism permits a more experimental approach toward institutions that can accommodate and be shaped by the diversity of modes of mental processing, communication and socialization that autism presents.

Key Words: autism, Foucault, Hacking

In his bestselling book, *An Anthropologist on Mars*, Oliver Sacks tells the story of how two autistics, Stephen Wiltshire and Temple Grandin, have discovered the hidden potential within their autism and have managed to lead interesting and fulfilling lives: Wiltshire as a budding artist and Grandin as an expert on animal behavior. The narrative frame adopted in Sacks' work is one of adaptation: autism is a neurophysiological fact that creates special challenges for the autistic person's endeavor to assimilate and adjust to the social world. While the spirit and tone of Sacks' work is progressive, his narrative glorifies the extraordinary adaptive successes of a select few autistics and tends to occlude the social and cultural influences that constitute autism. There is nothing rare or remarkable about this narrative frame in much of the literature on autism. Uta Frith, in a more scientific work, places her psychological inquiry in *The Enigma of Autism*, in a similar narrative frame. This way of framing the lives of autistic persons as stories of adaptation and overcoming has become an enduring feature of "the way we are learning to speak about autism" (Ian Hacking, 2009, pp. 499-516). In effect, such narratives accept the naturalness of the difference between norm and deviation, and fail to explore adequately the ways in which institutions and practices might change to accommodate the complexity and diversity of autistic persons and lives. This shift of emphasis away from conceptualizing autism as merely a neurobiological fact raises our awareness of how autistic persons can flourish when we adopt a more fluid, critical and experimental approach toward institutions and practices. The open and fluid communication norms and practices of digital communication and the internet offers an excellent example of an enabling and emancipatory social space for many autistic persons. Digital social space offers us some intimation of how autistic persons can flourish when practices are sufficiently supple, recognize the agency of autistic persons and cultivate an awareness of their own contingency. A dynamic co-adaptation of diverse modes of mental processing can flourish within practices that are both constituted by, and not merely constituting and confining, the fundamental plurality and diversity of autistic persons and lives.

Discourse and Niche: Has Autism Always Been with Us?

In his book, *An Anthropologist on Mars*, Oliver Sacks begins his account of the paradoxes of autism with the news story of “Blind Tom,” reported from the Fayetteville Observer of May 19, 1862:

“The blind negro Tom has been performing here to a crowded house. He is certainly a wonder... He resembles any ordinary negro boy 13 years old and is perfectly blind and an idiot in everything but music, language, imitation and perhaps memory. He has never been instructed in music or educated in any way. He learned to play the piano from hearing others, learns his airs and tunes from hearing them sung, and can play any piece on first trial as well as the most accomplished performer ... One of his most remarkable feats was the performance of three pieces of music at once. He played Fisher’s Hornpipe with one hand and Yankee Doodle with the other and sang Dixie all at once. He also played a piece with his back to the piano and his hands inverted. He performs many pieces of his own conception – one, his ‘Battle of Manassas’ may be called picturesque and sublime, a true conception of unaided, blind musical genius ... This poor blind boy is cursed with but little of human nature; he seems to be an unconscious agent acting as he is acted on, and his mind a vacant receptacle where Nature stores her jewels to recall them at her pleasure” (Sacks, 1996, p. 188).

While Sacks would condemn this reduction of autism to a public spectacle, his use of the story about “Blind Tom” is intended to show that autism has always been with us; that it is a naturally occurring phenomenon that we have only begun to see for what it is (Sacks, 1996, p. 250). On this view, the “epidemic” of autism is a product of progress in our ability to observe what was always already there, hidden in the neurobiological folds of the brain. We need only create the right diagnostic instruments and social institutions that will allow “autism to speak” and then we will be rewarded with the jewels that nature has hidden in the “enigma of autism.”

From the time of its almost simultaneous discovery by Leo Kanner and Hanz Asperger in the early 1940s, and throughout the 1980’s, autism remained a rare and intriguing oddity, with a prevalence of less than 0.5 cases per 1,000 (Craig J. Newschaffler, et al, pp. 235-58). More recent figures from the U.S. Centers for Disease Control estimate the prevalence rate of autism at 14.7 out of every 1,000 in the U.S. (U.S. Centers for Disease Control, 2013).¹ The dramatic increase in diagnosed cases of autism since the 1980’s might convey the impression that we have refined our sensitivity and become adept at searching for these “jewels of nature” that have long awaited our discovery. In this article, I hope to disrupt this impression with the disquieting suggestion that autism is not a brute fact brought about merely by some neurobiological event.² Multiple different axes of influence from different institutions and practices carve out a cultural “niche” within which autism appears (Hacking, 1998, pp. 51-79). When we view autism as a highly contingent category, we can begin to raise a number of questions that otherwise remain suppressed, questions that cannot be framed properly so long as we are entirely comfortable with finding autism defined in a *Diagnostic and Statistical Manual for Mental Disorders* and tracked statistically by our Centers for Disease Control. We might begin to see the manifold phenomena

of autism as a plurality of different modes of mental processing, of interpreting and living in the world, that are not well served by classification as a mental disorder or disease.

Autism is just emerging as an object of psychological study. Even as late as 2002, experts in the field were willing to admit, “We don’t know what autism is” (Lawson, 2003, p. 189). In his most recent book on autism, Stuart Murray nicely captures the paradox of autism research, “We know more about autism now than at any point in history ... yet, at the same time, if we’re honest, the central observation we might make, the ‘central fact’ about autism with which we should probably start, is that we don’t know very much about it at all” (Murray, 2012, p. 1). The endeavor to find a language for conceptualizing autism is still in its nonage, still plodding and provisional. We have only begun to measure the behavioral and cognitive dimensions of autism’s deviation from “the norm.” At this sensitive and impressionable point in the development of a scientific discourse, influences usually deemed entirely external to science are most visible. The work of Michel Foucault was devoted to drawing our attention to these early moments in the development of the human sciences, moments when the social and political threads woven into our standards of normality and deviance are most starkly evident. In the case of autism, we needn’t look back through history to the emergence of the distinction between reason and madness in the classical age; we can see that all the contingency and uncertainty of the human sciences are at play right before us, in our schools, hospitals and state bureaucracies.

Ian Hacking explicitly and Stuart Murray implicitly embrace and modify Foucault’s thesis that knowledge is always implicated in the norms of the society in which it is generated. Along these lines, our knowledge is both affected by and reinforces the limiting conditions of social action (Lemert & Gillan, pp. 57-58). To put this differently, knowledge is always “discursive;” it is always socially and politically porous. Foucault’s approach seems especially fitting in the case of an “epidemic” marked by impairment of normal social interaction, communication and play. Much of the popular and scholarly literature on autism contains the same features as the emerging discourse on sexuality in the nineteenth century, which Foucault discussed in the first volume of *The History of Sexuality* (Foucault, 1990). The emergence of scientific discourse on sexuality assumed that the relationship between sex and power had been one of repression and silencing; the emerging discourse would, it was assumed, be emancipatory by allowing the naturalness of sex to be brought into the open. Foucault shows us that the relationship between the new science of sex and human freedom is far more complicated. The relationship between sex and power had long been one of confession rather than repression. Pastoral power played a role in regulating the passions of the laity through the confessional centuries before the bourgeois confessionals provided by psychoanalysis (Foucault, 1990, pp. 18-22). In this emerging discourse, the relationship between knowledge and the individual was invasive. Knowledge expanded into the individual, inciting speech about new deviations, new threats to the maintenance of a controllable population with a stable set of sexual norms. Individuals are, thus, sexualized through a discourse on what is normal. While norms have apparently become liberalized since the nineteenth century, they have acquired a meticulous specificity, codification and appropriation by political concerns.

A similar structure is evident in the emerging discourse on autism. The exhortation popular in activist circles is to “let autism speak”- as if there were some truth about autism awaiting discovery, some truth outside the social practices and norms that have allowed autism

to appear in the first place. When we consider the discursive character of the human sciences, autism will not “speak” until society has found a way of inscribing its norms, in some unified and stable way, on the minds of those labeled autistic. This would grate against the growing popular conception of “the autistic mind” as some fact apart from the practices that allow autism to appear (Grandin & Panek, 2013, pp. 16-20). Like the discourse on sexuality, the discourse on autism is invasive, not repressive but confessional and productive. Far from silencing autism, the literature on autism produces a broad range of different ways of speaking about abnormalities and deviations from the norm. And the success stories of autism are measured by normalization – integration into the market through the cultivation of some extraordinary (super-normal) capacity, not unlike “Blind Tom.”

To understand autism as a “discourse” in the Foucauldian sense is to be mindful of the institutional and cultural horizon within which autism appears. This is not to say that there is no neurobiological dimension to autism or that every attempt to make an objective claim about autism is a gratuitous and arbitrary interpretation. Instead, it amounts to taking seriously the institutional, cultural and political conditions for the possibility of making certain observations and the ways in which the meaning of our observations are mediated by these conditions. Ian Hacking prefers the term “niche” to Foucault’s term “discourse” as a metaphor for the multiplicity of institutions and practices that create a cultural space for the appearance of mental disorders. Regarding his use of metaphor, Hacking writes:

“The metaphor of niche is my own, but there are many other metaphors in circulation. Readers of Michel Foucault have deluged us with descriptions of mental illness using the linguistic metaphor of discourse, or of a discursive formation. This is undoubtedly the most popular metaphor of the moment” (Hacking, 1998, p. 85).

Hacking finds this popularity a sad testament to the narrowness of contemporary social theory, which concentrates excessively on a narrow conception of language. The term “discourse,” Hacking avers, “does not do the work,” because it leaves the analysis at the level of how we talk about and categorize the world.

“Of course language has a great deal to do with the formation of an ecological niche, but so does what people do, how they live, the larger world of the material existence that they inhabit. That world must be described in all its peculiar and idiosyncratic detail (Hacking, 1998, p. 86).”

I am entirely in agreement with Hacking’s insistence on attending to the details and complexities of material life that lie on the margins of any discourse. But I also believe Foucault would have agreed. The shortcomings and narrowness of the discourse metaphor are largely the handiwork of Foucault’s many epigones. Both Hacking and Foucault focus on the “dynamics” rather than the “semantics” of classification. For both of them, this is a question of taking the cultural situation of the human sciences seriously. If we were to arrive at the point where we understand “the essence of autism” and would be able to claim with reasonable certainty that “autism is P” that would hardly resolve the complex question of the meaning of autism:

“How would the discovery of P affect how autistic children and their families

conceive of themselves; how would it affect their behavior? What would be the looping effect on the stereotype of autistic children? Which children, formerly classified as autistic, would now be excluded, and what would that do to them?" (Hacking, 1999, p. 121)

Understanding the "looping effect" of social norms on the sciences that reinforce those norms on the society and psyches that it studies is the core idea behind Foucault's notion of science as discourse.² A discursive approach to the question of autism raises new questions as it draws our attention to how culture and science, especially the human sciences, are intertwined. The neurobiological and psychological tools with which autism is diagnosed are woven into a larger tapestry of cultural narratives that color the perception of autism. Stuart Murray focuses our attention on how science and narrative are intertwined:

"Central to my sense of how we might understand autism is a desire to place the condition in cultural contexts, to see that the various opinions and theories that surround it are part of a wide fabric of narrative, representation, and characterization" (Murray, 2012, p. xiii).

Murray raises questions about the background cultural narrative within which autism appears. He repeatedly reminds us, "There are no biological markers for autism, neurological or otherwise" (Murray, 2012, p. 11). The MRI scans of autistics that show marked "underactivity" in the medial prefrontal cortex and the amygdala are not dispositive indications of autism. Neurobiological researchers are quick to point out that "knowing that brain structure or activity is different in those with autism does not locate this knowledge as a foundational cause of the condition" (Murray, 2012, p. 5). Autism appears through narratives, behaviors and social norms that are not reducible to some neurobiological condition alone. This is only one of the fibers woven into the tapestry of autism.

Myriad contingent influences generate the distinction between the normal and the abnormal in any given society, the contingency of this distinction is often "naturalized," giving the current norm a privileged status in the human sciences (Fausto-Sterling, 2000, pp. 5-16).³ The background assumption regarding the naturalness of autism is accompanied by the presumed naturalness of our current social norms. When we discard this assumption, we can then raise the question of how our social norms are implicated in the definition of autism. Instead of asking how we can make autism "speak," we might instead ask how society can speak in such a way that autism no longer appears as a disorder but as a constellation of different modes of cognition and socialization. This might reverse the usual way of framing the problem and turn the criteria for diagnosing autism back upon the society that has diagnosed it in such numbers. Instead of diagnosing autism as a qualitative impairment in communication and social interaction, we would diagnose our society as having a qualitative impairment in communicating and interacting with a diversity of cognitive and developmental processes. What is at stake here is respect for the autonomy and diversity of autistic persons in the face of a society that fails to see its own complicity in generating this new category of persons and that fails to recognize, accommodate and adapt itself to the radical plurality of persons diagnosed under the broad rubric of "autism." Narratives of adaptive success—of which Temple Grandin's life story has become

paradigmatic—contribute to the asymmetry of current institutions and practices and the plurality of autistic persons.

Autism and the “Repressive Hypothesis”

If we follow the narrative of Sacks or Uta Frith, we would be led to ask what happened to autistic persons in the past? The emergence of autism might be a story of ending the long suppression and exclusion of autistic persons throughout history. Frith offers her own litany of autistics from the past, including the “holy fools” of Russia and Victor—the feral child of Aveyron (Frith, 1996, pp. 16-17).⁴ According to this narrative, current psychology is liberating autism from centuries of misunderstanding and silence. Only now do we have the right diagnostic tools for identifying and remediating the disorder. The interpretation of autism as a disorder uncritically accepts and reinforces the adaptation frame I mentioned above, and it fails to see how the classification of autism as a disorder reinforces a present set of social norms and continues the work of suppressing and silencing autistic persons through a narrative of adaptation, overcoming and progress. To the extent that we think about autism in this way, we produce an elaborate discourse on a range of deviations from a norm. This kind of productive power is not repressive in relation to those so classified. It is productive on three levels: the production of a way of thinking about autism; reinforcing a set of normal behaviors—creating the institutional spaces necessary for that reinforcement—and producing a certain mode of existence or conception of the interiority of the autistic. The dynamic interaction of social norms, categories, behaviors and a sense of self is not, in itself, problematic; it is unavoidable. What is problematic is when this production takes place uncritically, through the rigid imposition of the presumed natural norm onto a population that is fundamentally plural. It is a common saying among autistic self-advocates that, “You only ever know one autistic person,” never autism as such. But if we follow Sacks or Frith, autism is a neurobiological fact that has been repressed and is only now coming into awareness and gaining the attention of our psychologists, psychiatrists, educators and the general public. The presumed naturalness of the distinction between normal and abnormal crates an asymmetric relation between the institutional norms and those classified as deviations. Individuals, institutions and practices falling within the norm needn’t adapt themselves to those deemed “deviant.” The only question for the “normal population” is how to facilitate the adaptation of the “deviants” to the norm or how to contain them and prevent them from disrupting normal practices. This narrative is not allowing autism to speak so much as it is producing the demand that autistic persons understand themselves and speak in a certain way. Foucault’s achievement in *The History of Sexuality* was to demonstrate how the scientific discourse on sexuality was not unique in its endeavor to bring sex into the light of discourse. The scientific study of sex, as it developed through the eighteenth and nineteenth centuries, thought of itself as liberating sex from centuries of silence and repression. By operating under this “repressive hypothesis”, the scientific study of sexuality inadvertently effected a continuation and intensification of the confessional strategy for accessing and normalizing the desires of the subject (Foucault, 1990, p. 11). The assumption that sexuality was a natural economy of desires, which finally found a voice in the scientific study of sex, only further articulated and reinforced the power of social norms in modern society.

The tendency to view autism as “a given,” that is, as a naturally occurring phenomenon, is a salient example of what Foucault termed “the will to knowledge”—an approach to the human

sciences that assumes a fixed epistemological point beyond social and political influences. The spuriousness of this position is especially evident in the case of autism, with its heavily socially laden diagnostic criteria: impairments of social interaction, communication and abnormally repetitive patterns of play (DSM V, sec. 299.00). While much of the literature acknowledges the breadth and vagueness of the diagnosis, little emphasis is given to the norms and practices of the society from which the diagnostic criteria emerge. Those authors who are especially sympathetic to the experience of autistic persons are likely to see the relationship between autism and society (or autism and power) as one of repression— in a way that reiterates the problem of the “repressive hypothesis”. On this view, normal social practices present a special challenge for autistic persons, who are faced with the Herculean task of having to internalize the complexities of social interaction one piece at a time.

In accord with the repressive hypothesis, the great success stories of autism valorize the cases of successful adaptation to society, usually through the discovery and cultivation of extraordinary abilities. While the “hidden treasure” of autism has always been with us, we are only now learning how to unearth and harness the “special powers of the autistic mind”.⁵ Autism can find a market niche, as it seems to be the primal fund of valuable cognitive oddities. If only we could free autism as Grandin has, the epidemic would lose its sting.⁶ The popular impression conveyed by the valorization of Grandin is that autism can be extraordinarily useful when we are aware of the difficulties involved in properly integrating the autistic population. Against many of Grandin’s own warnings, her story has taken on the status of a paradigm for how to be autistic, how to find a way of successfully adapting to a world that categorized you as abnormal.

Foucault’s work draws our attention to how the purportedly emancipatory discourse on sexuality served a similar paradigmatic function. Far from freeing desire to manifest itself in various ways, sexual liberation has told us how to be sexual; how to look, how to interact; how it is and what is “normal” to desire. I mentioned above Foucault’s revelation that modernity has completely misunderstood the relationship between power and sexual discourse. The mistake was to view this relationship as one of silencing and repression. Instead, the anxiety about sex required its complete and meticulous disclosure. Foucault writes:

“This is the essential thing: that Western man has been drawn for three centuries to the task of telling everything concerning his sex; that since the classical age there has been a constant optimization and an increasing valorization of the discourse on sex: and that this carefully analytical discourse was meant to yield multiple effects of displacement, intensification, reorientation, and modification of desire itself” (Foucault, 1990, p. 23).

In this connection, Sade and the anonymous author of *My Secret Life* were misconstrued under “the repressive hypothesis” as voices of liberation opposed to the dominant impetus of sexual discourse. Instead, Foucault allows us to see them as “naïve representatives of the injunction to talk about sex” (Foucault, 1990, p. 22). While Temple Grandin and the Marquis de Sade contribute to entirely different fields of inquiry, one cannot help seeing the same naïve role played by Grandin’s narratives in the discourse on autism. Grandin’s biography is an account of how autistics can adapt to the constraints of our society as it is – the narratives hold out the hope that other autistics can earn doctoral degrees and become independent, successful members of society with a litany of contributions to industry and commerce. The narrative risks becoming

the paradigm for how autism must speak and behave in order to adapt to modern bourgeois society.

While the stories told by Grandin and Sacks are inspiring, they are not attentive to the ways in which autism reflects social practices and norms. Grandin and Sacks are salient examples of the repressive hypothesis at work in the popular discussion of autism. For all of their admirable work in drawing public attention to autism, they misconstrue the relationship between autism and power as repressive and silencing. This is hardly the case. In a way strikingly similar to the discourse on sexuality, there is an “incitement to discourse” about autism – an incitement fueled by fascination and anxiety. The fascination ignites upon the disparity between the sub-normal and the super-normal, the idiot and the genius entwined in the popular fantasy of autism (See Hacking, 2010). It is typical of both scientific and popular literature on autism to comb through historical accounts of eccentric personalities in search of the criteria in the DSM V. For example, Sacks writes, “Autism, clearly, is a condition that has always existed, affecting occasional individuals in every period and culture. It has always attracted in the popular mind an amazed, fearful, or bewildered attention” (Sacks, 1996, p. 190). This hypothesis leads us to view autism as external to society, as a condition of the psyche in the state of nature (Frith, 1996).⁷

The narrative thread woven through Grandin and Sacks contributes to a discourse on autism that construes successful integration as freedom. In the *History of Sexuality, Volume 1*, Foucault writes: “in order to speak about sex, we must cleanse it in a discourse about freedom.” We might paraphrase Foucault, here, to say that in order to speak about autism, we must cleanse it in a discourse about the cleverness, resourcefulness and adaptability of autistics to our society. Less than 10% of those diagnosed with autism have exceptional abilities and a slim fraction of that group has had the adaptive success of Temple Grandin (Mesibov, 1997). Yet this fascination with exceptional abilities drives much of the discourse and the solicitousness and anxiety with which the families of autistic children are inscribed by medical and educational institutions. The tone of the literature suggests that parents ought to be ever vigilant for the appearance of superpowers in their autistic children. Anxiety over the myth of “cold parenting” as the cause of autism has been replaced by anxiety over finding the “special powers” of autistic children, powers that will ease their transition to social utility and marketability. This anxiety of integration enervates every institution touched by autism. The family, schools, hospitals and the state are all charged with the governance of autism – all are challenged to manage autism while causing a minimum of friction with existing institutions.

The Vulnerable Autonomy of Autistic Persons

The adaptation narrative that we find woven into much of the popular literature on autism prevents us from taking a more dynamic and experimental attitude toward the social institutions and practices that present obstacles to the multiplicity of ways in which autistic persons may develop and flourish. The popular narratives of autism share Sacks’ tendency to naturalize the boundary between the normal and the abnormal in a way that privileges the norm and requires the adaptation of autistics to the smooth functioning of the existing configuration of institutions and interests. In this sense, the discourse on autism is political through-and-through. When we consider that only a small fraction of the autistic population is (possessed of exceptional abilities)

capable of even the vaguest imitation of Grandin's success story, it should be a matter of concern what will happen to the other 90% who are not going to follow in Grandin's footsteps. By naturalizing autism and the boundary between normality and abnormality, the contemporary discourse serves to legitimate the current regime of institutions and practices that govern the lives of autistic persons. The "epidemic of autism" creates enormous friction within educational, medical and social welfare institutions. Advances in educational and medical testing, screening, and support that have contributed to the appearance of autism also interpret autism as a regulatory risk to the smooth functioning of our educational and public welfare institutions (Nadesan, 2005, p.3). When our educational environments fail to meet the needs of autistic students, the autistic child is considered to be "in crisis." The narrative of adaptation prevents us from reversing this interpretation and recognizing the crisis of institutions themselves in accommodating diverse modes of mental processing, communication and behavior that fall under the rubric of autism.

The need for this reversal is urgent in light of how political and regulatory thinking has evolved. While in everyday political parlance, we use the language of 17th and 18th century liberalism – rights, equality, liberty – our experience is marked by the subordination of liberal values to bureaucratic functions that follow a logic of their own. Many attempts have been made to understand this rift between the substantive values of modernity and the instrumental, seemingly value neutral reasoning that governs everyday life. Max Weber, the members of the Frankfurt School, and others have devoted their work to understanding how an enlightened and civilized world could collapse into global war and genocide. Foucault's approach to this problem focuses on the ways in which the administration of public health has invaded spheres of life that were once considered private, or at least not a matter of governmental concern, and how this mode of administration becomes more important than the lives of those it administers. This approach makes Foucault one of the first theorists of politics at the regulatory level. The level at which autistic persons and their families encounter it in their everyday lives.

Foucault's account of this trend in modern political thought helps us to understand how the regulatory approach to autism can be paradoxically both invasive and minimalist. It is invasive in its assessment of whether or not the autistic child constitutes a threat (a risk of harm to self or other) and minimalist in its approach to how much educational service or therapeutic care the autistic child should receive.

Policies regarding education and medical treatment are shaped by the overlapping imperatives of fiscal frugality, market integration, and social stability. These imperatives not only shape the policies and regulations that govern autistic persons, but also how they function in accord with their own internal limits, utilizing institutions and powers already in place, already shaped by the imperatives of utility and the market. Viewed in this way, the "epidemic of autism" is, in part, a measure of the inertia of these institutions in the face of neurodiversity, giving rise to new strategies for normalization and conformity. This is perhaps what poses the greatest risk to those who are diagnosed as being "on the spectrum." Foucault's account of the appearance of the modern homosexual in the 19th century relates how their expulsion from the community at large allowed them to occupy a limited social space which allowed them to be studied and objectified into a type (Foucault, 1990, pp. 43, 101). In the case of autism, it is the

dispersal of the autistic population that makes their specification relevant in the regulation of so many other associations, not only the medical practice, but also the school and the family.

A close administrative apparatus follows the autistic child through every institution she touches, but the different spheres of family, social welfare and education are not governed by a single, coherent administrative logic or language, as Foucault's account of biopolitics would suggest. There is a marked difference in how autistic persons appear, and are expected to "perform," within medical and educational practices. Autism appears and receives attention and services only as a set of "maladaptive" behaviors that constitute a threat to self or other (Nadesan, 2005, p.2).⁸ In this register, the needs of the autistic person are interpreted as a risk (even a threat) to the security of the community. Medications and therapy are provided to hold the most harmful symptoms of the "illness" at bay. For all of the invasive administration this entails, there is still a minimalist logic governing the medical assistance apparatus: only the services sufficient to allay the "risks" presented by autism should be provided, and nothing more. Within this vocabulary, it is impossible to conceive of autism as a difference in processing and in self-awareness that might flourish under the right conditions. This biopolitical concern about "not governing too much" is, as Foucault described it, both invasive (in its categorization and detection of autism and its "risks") and minimalist (in treating autism as a disease with controllable, remediable symptoms and nothing more). At least formally, the vocabulary of the educational institutions mitigates the interpretation of autism as a risk to social welfare. Emphasizing the particular needs and talents of each individual student drives the formal discussion. Nonetheless, the practical struggle to achieve an educational plan that is actually individualized faces the same minimalist logic that governs the medical decision-making. Greater emphasis is placed on providing the resources necessary to keep the child within the "normal" educational course. Special emphasis on strengths, especially strengths that might lead to classroom innovation, or more full-time teaching staff, has to be fought for every year with school administrators. In spite of this institutional inertia, it is possible within the educational setting to speak of autism as a neurological difference that can flourish under the right conditions. But often the administrative logic of medicalization deals with autism as something to be treated, cured, or contained, in ways that minimizes the need for institutions to adapt to the challenges presented by autistic people. Often this institutional logic invades educational decisions. On this reasoning, the educational demands of the autistic child have been met when they no longer constitute a risk to the smooth functioning of the school, or no longer engage in behaviors that constitute a threat to staff.

Autism and Political Agency

The more we accept a narrative of autism as a neurobiological impairment merely, and not also a product of institutions and practices, the more we subject autistic persons to diminished autonomy and reciprocity. The classification of autistic persons by established practice is not a one-way street, nor is in an unalterable asymmetry of governmental power over autistics, as the tone of Foucault's works often suggests. Hacking and Nadesan have explored the notion of autism as an "interactive kind:"

"Interactive kinds are classificatory systems that emerge within complex matrices of institutions and practices. Once articulated, these classificatory systems

engender practices and institutions, having the effect of producing what was classified” (Nadesan, 2005, p. 24).

But interactive kinds are not passive in the face of their classification; they are not merely the passive subjects of institutional power:

“The process of producing human beings is subject to effects unintended because, among other factors, of the reflexive nature of consciousness. Awareness of one’s classification as a particular kind of being, a particular kind of subject, can engender resistance and/or behavioral variation” (Nadesan, 2005, p. 24).

The resistance of autistic persons to classification as having a disorder, or a disease in need of a cure, or an essence that captures the meaning of their experience, has evolved through other practices that emerged parallel to autism. The role of the internet in the development of this resistance has been crucial.

The criticism of the NYU Child Study Center’s “ransom notes” campaign is an eminent case of autistic self-advocacy facilitated by the Internet (Kras, 2010). In an attempt to raise public awareness about autism, the NYU Child Study Center disseminated “ransom note” ads that read: “We have your son. We will make sure he will not be able to care for himself or interact socially as long as he lives. This is only the beginning. – Autism”. The ads were posted on billboards throughout New York City on December 7, 2007, and were immediately met with such intense and well organized resistance from the Autistic Self-Advocacy Network that the Child Study Center decided to pull the ads on December 19. It is worth noting that while the ads appeared only in New York City, the resistance to the campaign was global. The internet facilitated a resistance that was global and also plural, offering autistic persons a way to define and interpret their own experience in all of its complexity, and to refuse the interpretation of their lives as invalid hostages of autism. By challenging long-standing norms of communication— the bodily cues that require a narrow sensory focus and range of interpretations – the internet has served as a medium for many autistic persons to communicate and to offer their own interpretation of their experience and its meaning (Hacking, 2010).

The openness of cyber space to the particularity and diversity of autistic persons and modes of communication has yet to be followed by a similar openness in the physical spaces of the social world, schools and communities. A formal legal recognition of the need for individualized accommodation for education and job-access is not sufficient, especially when this recognition is shaped by a cultural narrative of one-sided adaptation of the autistic individual to society -- rather than the co-adaptation of society and individual and the flourishing of a multiplicity of forms of processing, communication and living. The abiding inflexibilities of the basic social institutions that serve as a threshold to economic security and independence -- job application processes, interviews, networking; acclimating to new procedures and routines at work; participation in group projects; adjusting the sensory demands of the workplace; and organizing and managing tasks that require integration with a team – all present challenges yet to be remediated (Robertson, 2010). Even in the face of this inertia, there has been some success in adjusting the workplace to the unique needs of autistic persons. This is only a very small step in the right direction. Progress in contouring the social and institutional space of higher education

to allow access for autistic persons remains modest at best. Currently only a handful of universities offer specialized programs for autistics (Robertson, 2010).

I cannot conclude this article with a blueprint for the revolution; I only hope to have provided some intimation of the barriers created by an adaptation narrative and how this prevents a more dynamic and experimental attitude toward the institutional situation of autistic persons. The pace at which different scientific accounts of the cause of autism are enthusiastically and confidently generated and embraced only to be discarded with as much alacrity offers us an excellent case-study in the contingency and arbitrariness of the human sciences, to which Foucault, Hacking and a more careful reading of Grandin's work draws our attention. Ian Hacking has written of the emerging discourse on autism: "We are participating in a living experiment in concept formation of a sort that does not come more than once in a dozen lifetimes" (Hacking, 2009). Stuart Murray also sees autism as a phenomenon filled with possibility and "having the potential to renegotiate the terms of the human" (Murray, 2012, p. 104). My hope is that we face this challenge with an experimental attitude toward the contingency of our current regime of institutions and practices. We should be optimistic about what lies beyond the limits of the current discourse on autism. The frantic and failing attempt to impose a coherent etiology or definition of autism is emblematic of our growing awareness of the contingency of our social norms and the loosening of their hold on the possibilities for fashioning (and defining) the human. It is an opportunity, not to dedicate ourselves to discovering the "truth" about autism, but to recognize this failure as the opening of a space in which we can think about what is possible.

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Endnotes

¹“Autism and Developmental Disabilities Monitoring,” U.S. Centers for Disease Control, accessed May 20, 2015, <http://www.cdc.gov/ncbddd/autism/addm.html>.

² This is not the place to settle scores between Hacking and Foucault. There are substantive differences between them, especially regarding the possibility of emancipatory practices. See Hacking’s embrace of C.S. Peirce’s notion of the community of inquirers, for instance. Hacking, *Mad Travelers*, 93.

³ Anne Fausto-Sterling offers an impressive account (largely inspired by Foucault’s approach) of how social norms have affected the medical practices dealing with infants born with ambiguous genitalia.

⁴ “Autism is not a modern phenomenon, even though it has only been recognized in modern times. In view of the short history of psychiatry, and the even shorter history of child psychiatry, we know that a disorder recently described is not necessarily a recent disorder. An increase in diagnosed cases does not necessarily mean an increase in cases. There are tantalizing hints of Autism in the medical records of history.” Uta Frith. *Autism: Explaining the Enigma*. (Cambridge, MA: Blackwell, 1996), 16-17.

⁵ Temple Grandin is almost a household name among those familiar with autism. Grandin has written two well-known autobiographical books on her successful struggle with autism: *Emergence: Labeled Autistic* (New York, NY: Warner Books, 1996) and *Thinking in Pictures: My Life with Autism* (New York, NY: Vintage, 2006). She holds a Ph.D. in animal science, which she teaches at Colorado State University.

⁶ Grandin is far more self-aware than many of her admirers regarding the idiosyncrasies of her personal story. Temple Grandin. *Thinking in Pictures: My Life with Autism* (New York, NY: Vintage, 2006), 26-31. The use of her life as a paradigm case of “overcoming autism”—a use she herself resists – is what is addressed here.

⁷ In *The Enigma of Autism* (1996) Uta Frith offers an example emblematic of this view of autism a natural and ahistorical condition. Frith applies the diagnostic criteria for autism to Victor, the famed Wild Boy of Aveyron, who was found roaming the forests of central France in 1785.

⁸ Nadesan writes of her experience with her autistic son, Kamal: “autism has a performative component, as known by every parent who struggled to meet the criteria for government and educational services for their child. For the social services agent, I must stress (and even exaggerate) Kamal’s maladaptive behaviors. For his teachers, I stress Kamal’s high intellect in order to avoid having him labeled as “mentally retarded.”

The Big Bang Theory: Mad Geniuses and the Freak Show of Higher Education

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Abstract: This essay discusses the television comedy series *The Big Bang Theory*. Through lead characters including physicist Sheldon Cooper, the series portrays higher education as a metaphorical freak show, and academics as geeky mad genius freaks. Implications for constructions of disability in higher education are discussed, with recommendations for future research.

Key Words: disability, higher education, television

As of fall, 2013, *The Big Bang Theory* (*TBBT*) on CBS is the number-one comedy for viewers ages 18-49 in the United States (Bibel, 2013). When it premiered in 2007, critics expected the show to fail. CBS was perceived as a network for old people, the traditional sitcom format was no longer “cool,” and no one believed four geeky Sci-fi-loving Caltech research scientists could possibly be funny (Goldblatt, 2007; Hoerburger, 2013; Jurgensen, 2008; Weinman, 2008). Much of its acclaim since then has gone to Emmy and Golden-Globe winning actor Jim Parsons, who plays physicist Sheldon Cooper on the show.

This essay examines Sheldon Cooper and the other lead characters, the majority of whom are portrayed as scientific researchers and academics at CalTech. While the character of Sheldon is widely presumed to be autistic by media critics, *TBBT* viewers, and autistic activists, I interpret his character as a new incarnation of the “Mad Genius” trope for the 21st century. I then discuss the implications of this new geeky reincarnation of the “Mad Genius” (i.e., “Mad Scientist”) in academia as a cognitive freak whose stage show is higher education, the one place where neurodiverse freaks and their accommodations may be portrayed as “normal.” I conclude by problematizing *TBBT* as simultaneously funny, progressive, and problematic for disability studies scholars, with recommendations for further research and analyses.

Images of Higher Education and Disability in U.S. Culture

Many television and film stereotypes of academics (e.g., professors, researchers) are rooted in campus novels about students (which first appeared in the 19th century) and academic novels about faculty (which began in the 1950’s) (Leuschner, 2006). These fictional accounts of college and universities crafted several persistent stereotypes of college instructors. There was the absent-minded professor, a milder, gentler version of Frankenstein-esque mad scientists presented in earlier texts and films (Leuschner, 2006). A second typology was also a metaphor for corruption in the male-dominated world of higher education – the professor who is overtly or covertly lecherous or sadistic (Leuschner, 2006). Academic novels contributed to many of society’s understandings about the process of becoming faculty, with tenure evolving from a somewhat benign process protecting the “status quo” to something enabling unethical, comedic, or “rogue” behavior (Leuschner, 2006, pp. 339-340).

Films later refined these unfavorable images of academics. Research by Dagaz and Harger (2011) analyzed depictions of professors in primary or secondary roles of popular films from 1985 to 2005, and found that in general, professors in films were more likely to be men under the age of 60. The majority (88 percent) were White, with African-Americans over-represented, and Asian and Hispanic professors under-represented. Racial and gender stereotypes among characters were common. For example, male professors were never in the field of education, and were usually disinterested in teaching, which was portrayed as more nurturing and feminine. Instead, males focused on research, to the extent that ethics were often secondary to productivity. Female professors on the screen were under-represented in medical and science fields and were usually working in the humanities, conforming to traditional gender roles. Females were also more likely to be sexualized secondary characters; when they had tough masculine characteristics, these were mediated by emotional or feminine scenes that served as dramatic plot points. No African-American, Asian, or Hispanic professors were in business or in science, technology, engineering, and math (STEM) fields, except one African-American woman who was simply a love interest for the male lead. When they appeared, African-American professors were more likely to carry a “mark of distinction” (p. 280), like glasses or bowties, as props to legitimize them as visibly non-traditional professors.

On television, higher education is still rarely a focus for an entire series, with only a few shows like *Felicity*, *Community*, or *A Different World* being entirely about college, and a few others like *Third Rock from the Sun* and *Beverly Hills 90210* making academia the backdrop but not the focus. In *90210*, for example, college life was glossed over, avoiding discussion of controversial politics, authoritarianism, diversity, and even academics, for the sake of focusing on the Greek system, extracurricular activities, and relationships between characters (Byers, 2005). Intellectualism and academics were not portrayed positively, and fears about jobs, scholarships, or money were practically non-existent (Byers, 2005; Leuschner, 2006).

In most series, like *How I Met Your Mother*, *The Vampire Diaries*, or *Glee*, college is a vehicle for plot points. College becomes a way to deal with characters who are working as professors or growing older and leaving high school; college may also become a metaphor for broader themes of the show. On television, as in movies, researchers have noted that faculty typically are intimidating, disconnected from students’ lives, boring, older, and White, with their own best interests at heart and a willingness to set aside ethics for the sake of their research, meaning students are often portrayed as more moral than their professors (Byers, 2005; Rogers, 2012).

If images of higher education are rare in television and film, explicit images or discussion of disability in higher education are practically non-existent. Professors and students with illnesses or disabilities do appear, like when characters in *Beverly Hills 90210* dealt with a friend’s HIV+ status (Byers, 2005). Disabled people are sometimes portrayed as members of outsider groups of rejects, like a wheelchair user and a blind man in the *Revenge of the Nerds* films (Dolmage, 2013). In many movies or television shows, however, freakish or disabled characters are not identified as “disabled” *per se*, like the vampire graduate students in the 1995 film *The Addiction* (McDermott & Daspit, 2005), or the freshmen vampires in television’s *The Vampire Diaries* who try to figure out how to pass as “normal” while hiding blood bags from roommates in the dorm. Leuschner has noted that professors portrayed as “ill,” “defective,” or

“deformed” can be metaphors for institutional, social, or systemic problems with the “academic body” of higher education (2006, p. 340). In some cases, the university can even seem like an asylum or a nursing home – an institution that is metaphorically institutional in the traditional sense of the word (Leuschner, 2006). Faculty members can also have major disabilities or minor ailments (e.g., being overweight or older) to humanize them in comparison to their colleagues (Leuschner, 2006).

This essay looks at characters in *The Big Bang Theory* (*TBBT*), a television show revolving around seven main characters; six are scientific researchers, and five of those six are working in academia. However, rather than being a show about college and student life, or a show where college is simply a vehicle for other plot points, their research and science itself are the major focus of the show (as evidenced by the title of the series). The show has a science consultant, features frequent Nobel Prize winners as guests, and doesn't hesitate to use academic or science jargon that is nearly unintelligible; indeed, that is part of many running gags. It is known for being extremely popular with scientists and self-proclaimed nerds and geeks, and real-life scientists are often recruited as extras for campus scenes (Dreifus, 2013). *TBBT* is also notable for being a show about disability in higher education. In the remainder of the paper, I examine *TBBT*'s lead characters as disabled, and explore what messages about disability and higher education *TBBT* may convey.

Sheldon and Colleagues as Disabled: Mad Geniuses of Academia

The Big Bang Theory started out as a series about four Caltech research scientists who fit well-known stereotypes and tropes of prime-time comedies: Leonard, who seems normal but never quite succeeds at actually being normal; Howard, an outgoing horny misogynist who is terrified of women; Raj, the starry-eyed astronomer with traditionally feminine characteristics who becomes mute every time a woman is in the room; and Sheldon, a genius who has been in universities since fifth grade, but can't comprehend the simplest social norms even when he reads the latest research on the subject. As a foil for these men, the character of Penny, who lives across the hall, was supposed to be the “normal” one who knows pop culture and society, dates, has a sex life, is pretty, and is an actress/waitress who is smart but never attended college. In the fourth season, the show added Amy, Sheldon's friend who is a girl (eventually called a “girlfriend”) who is as geeky as Sheldon but slightly more ambitious about a social and somewhat kinky sexual life outside of her work as a neurobiologist. Howard dates and eventually marries Bernadette, a microbiologist working for large companies who is also a bridge between the normal and geeky worlds of *TBBT* lead characters: buxom, blonde, and a former waitress, but possessing a Ph.D. and just as smart as Amy or the guys.

While following a traditional sitcom format of a live audience, and relying on traditional sitcom humor about bodies, gender, race, sex, and often low-brow fare, the show offers a twist by having much of the humor reference science and geeks instead of seemingly “normal” topics and people. Over time, the show began slowly evolving around the character of Sheldon Cooper, who does not want to be normal, and frequently wishes the normal world would leave him alone (Weinman, 2008). Executive producer Bill Prady has said that as the show continues, “Anything that upsets the ecosystem in [Sheldon's] world seems to turn out good scripts” (Rice, 2009, n.p.). Sheldon is a tall theoretical physicist who almost always wears sci-fi t-shirts (with anything

about the Flash showing up frequently). He looks nothing like a typical leading man on television (Kelly, 2011), and was once described as having a voice that is “haughty and patrician, but also slow and faintly Southern – almost as if Katherine Hepburn had morphed into the church lady” (Kelly, 2011, p. 84). He is a geek who seems completely unlovable in many ways, but is never (or at least rarely) intentionally malicious, drawing out viewers’ empathy and sympathies, even while he is clearly unable to adequately comprehend or manage those same emotions himself (Sheffield, 2010).

Sheldon is frequently perceived to be “the most obviously autistic character on television” (Heilker, 2012, n.p.) by TV critics, psychologists, and even autistic self-advocates and activists, usually because of his obsessiveness, immersion in fictional worlds of science fiction, frequent avoidance of eye contact, and difficulty in handling emotions and social niceties (Bartlett, 2009; Bednarek, 2012; Bibel, 2010; Kelly, 2011; Walters, 2013). Examples of Sheldon’s “social incompetence” include saying the best part of friends on MySpace is not having to meet face-to-face, having to be told when gift-giving is a “non-optional social convention,” and noting that video games are better than sex because it has “high-def. graphics and enhanced weapon systems” (Weinman, 2008, p. 71). Even the actor Jim Parsons, who plays the character of Sheldon, has said, “Thinking [Sheldon’s] autistic is an easy leap for people watching the show” (Walters, 2013, p. 275).

But Parsons also explained that *TBBT* writers deliberately refuse to diagnose or label Sheldon as having Asperger’s or autism, with the show preferring to utilize some autism-like traits while also having the flexibility of moving beyond those labels and any societal assumptions or presumed implications (*Time*, 2011). Indeed, there is not a single reference in the series to Sheldon as autistic, although there are running jokes about him being a robot or alien, or rusting if he cried (e.g., “The Fuzzy Boots Corollary” (1.03); “The Proton Displacement” (7.07)). The show deliberately keeps viewers guessing about Sheldon. For example, *TBBT* creator Chuck Lorre has expressed frustration about fans wanting Sheldon to “hook up” with his girlfriend Amy, saying it’s more interesting to have a character choosing not to have typical romantic and sexual relationships (Rice, 2009). Mayim Bialik, who plays the character of Amy, has a doctorate in neuroscience in real life (like her character Amy on the show). Bialik has said Sheldon could probably not be formally diagnosed as autistic if he was a real person (Bibel, 2010).

Bialik does, however, believe the characters of Sheldon and Amy could possibly be diagnosed with Obsessive-Compulsive Disorder (OCD) (Bibel, 2010). Sheldon has many traits that could be called obsessions, including: a propensity to label everything, including the labeling machine; needing to knock three times when going to Penny’s (knock, knock, knock...’Penny’...knock, knock, knock...’Penny’...knock, knock, knock...’Penny’); a rigid interpretation of the lengthy roommate agreement he has with Leonard, including contingencies for zombie attacks and bowel movement time tables; a possessiveness about his “spot” on the couch; and an immersion in whatever is occupying his thoughts at a moment, whether or not anyone else is interested.

For the purposes of this paper, however, the exact diagnosis of Sheldon or any other character is not critical. I readily acknowledge that none of *TBBT* characters are ever explicitly

defined with the label of “disability;” nor do any of the characters identify themselves as disabled or members of a disability community. To identify “disability” on *TBBT*, I drew upon several definitions, since there is no universal definition among medical professionals, policymakers, or disability studies scholars (for further discussion, see, e.g., Altman, 2001; Williams, 2001).

I chose to label *TBBT* characters as disabled if they (as characters on the show) had a specific diagnosis for any kind of impairment, illness, medical condition, or psychological disorder, or if *TBBT* showed them receiving medical treatment for something. This follows what many disability studies scholars would see as a “medical model” definition of disability, where disability is usually negative, meriting a cure or medical remediation. It is an individual condition, diagnosed by medical professionals. Examples of this would include allergies, severe near-sightedness, or lactose intolerance.

But in looking for “disability,” I also looked for physical, mental, and emotional impairments, illnesses, health conditions, or other physical traits marked as significantly “different” by other characters on the show, whether positive or negative (provided that they were not directly related to race, ethnicity, or gender). The difference also had to go beyond a one-time mention or casual quirkiness (as discussed in Hirschorn, 2007), and be mentioned, joked about, or alluded to in multiple episodes or by multiple characters. Whether or not they could correlate with a specific medical diagnosis is not as relevant as the perceived physical, mental, or emotional difference itself. Examples of this would include Howard’s relationship with his mother, Bernadette’s annoying voice, and Sheldon’s high IQ.

Even though this second definition of disability is obviously subjective and problematic, it is consistent with other scholars who have done critiques of disability in film, television, and media (e.g., Adams, 2001; Bogdan, Biklen, Shapiro, & Spelkoman, 1982; Elliott, Byrd, & Byrd, 1983; Lawson & Fouts, 2004; Leuschner, 2006; McReur, 2006; Walters, 2013). More consistent with a “social model” or socio-political perspectives of disability, this definition presumes disability, like race and gender, is socially constructed and actually remains in a state of flux, depending on context and who is doing the perceiving (an especially important consideration when discussing fictional characters viewed by a television audience).

This means some characteristics (like Howard and Bernadette being very short) may not be true “disabilities” defined by medical professionals or political and legal frameworks. On the show, however, the constant commenting, jokes, and problems resulting from their height mark their stature as “different;” the physical nature of it therefore also marks it as “disability.”

Likewise, Raj’s repressed gay tendencies, preferences for traditionally feminine activities, and “ersatz homosexual marriage” to Howard (“The Maternal Capacitance” (2.15)) are all running jokes on the show and a major focus in multiple episodes (e.g., “The Transporter Malfunction” (5.20), “The Closure Alternative” (6.21)). While feminine traits, being gay, or being a metrosexual-like character certainly isn’t a disability, on the show, this set of traits merits jokes from other characters, is perceived as positive or negative in different situations, is identified as an emotional, mental, and physical difference, and manifests in Raj experiencing barriers and limitations. In other words, it becomes a “disability” for Raj on *TBBT*. This flexible

definition evolving from *TBBT* itself also allows for critique of how interactions between characters, multiple attributes of characters, and different environments may work together in shaping constructions of disability.

Returning to a discussion of Sheldon, further evidence of Sheldon as mentally disabled (i.e., a more current term for “mentally ill” or “psychologically disabled,” as explained by Price, 2011, p. 9) is the fact that while no other characters call him autistic, they frequently call him “crazy,” “insane,” “nuts,” and terms like “Dr. Wackadoodle.” This occurs even when they are being affectionate or talking about him fondly. The discourse within *TBBT* is not that Sheldon is autistic, but that he is a “mad” genius, a “nutso” nerd, or a “crazy” geek.

One popular line from the show that has made its way onto several memes and t-shirts is Sheldon’s varying and recurring versions of “I’m not insane...my mother had me tested” (see, e.g., “The Griffin Equivalency” [2.4]). The reason this is funny is not only because everyone, including viewers (and Sheldon’s fictional mother), think Sheldon is “crazy,” but also because the joke pokes fun at the limits of *TBBT*’s precious science, which clearly missed the mark on diagnosing Sheldon while being revered by all the main characters on the show. At the same time, Sheldon is quite rightly telling everyone that he’s not really the crazy one – the so-called sane people are insane. The joke is on Sheldon, science, the viewer, definitions of normal, and assumptions about craziness and madness. In fact, it could be argued that all lead characters who are academics or researchers display some form of “mad genius,” diagnosed disability, or ambiguous impairment; even Penny could be included, despite her lack of an advanced degree or position in higher education (see examples in Table 1). These range from vague disorders like Sheldon’s skin conditions (which are discussed and thoroughly medicated by Sheldon but never seen), to conditions that are not currently defined as disabilities in society; they only become impairments on the show when characters refuse to acknowledge them or accept support for them (like Raj’s supposedly “repressed homosexuality,” Bernadette’s short-fused temper or egomania, or Howard’s dysfunctional relationship with his mother). Some are diagnosed and viewers have seen characters seeking medical options to treat them, like Raj’s social anxiety or Howard’s severe allergies. If mental illness, impairment, sickness, or deformity (even without an official label or diagnosis) can be identified as disability (Titchkosky, 2009), then all the professors and researchers on *TBBT* are disabled.

Table 1. *This table shows the main characters on The Big Bang Theory and their explicit or implied disabilities, illnesses or ambiguous impairments.*

<u>Character</u>	<u>Examples of Disabilities, Conditions, Illnesses, and Ambiguous Impairments</u>
Raj Koothrappali	Selective mutism around women (resolved by Season 7), which evolved from urinary incontinence and mutism. Social anxiety. Unacknowledged gay desires and traits defined as traditionally feminine.
Leonard Hofstadter	Lactose intolerance, extreme myopia corrected with lenses, asthma, carsickness, skin sensitivities, genetic heart disease.
Bernadette Rostenkowski	Very short. High-pitched voice. Temper that flares and resolves quickly; hyperaggressive (especially in competitions), with occasional bouts of mania and egomaniacal behavior. Questionable ethics, behaviors, and lackadaisical attitudes about the infectious disease specimens she and her colleagues handle.
Penny	Struggles with managing temper, insecure, easily addicted to anything from wine to videogames. Seems to be “catching” geekiness from others over the course of the series. Some characters refer to her as being pathologically messy, disorganized, and inattentive to details. Implied possible complications from mother smoking pot while pregnant and father raising her like a boy.
Amy Farah Fowler	OCD and autistic traits, seems obsessed with female-to-female and kinkier forms of sex. Originally resists social norms and dating, but eventually forms friendships and embraces social life.
Sheldon Cooper	Extremely high IQ. OCD and autistic traits: little to no interest in sex, difficulty with social norms, patterned behavior with difficulty varying from schedule. Hypochondriac about minor symptoms. Various undefined skin conditions. Frequently called crazy.
Howard Wolowitz	Hypersexual but afraid of women for first four seasons. Inferiority complexes about height, skills as a husband, and not having a doctorate. Complex relationship with mother that has been called pathological. Multiple allergies, including peanuts. Asthma and congenital heart condition. Language savant (polyglot).

Even minor roles of academics on *TBBT* portray professors and researchers on campuses as geniuses who are also insane. Colleagues of the lead characters are nearly always portrayed as being on the verge of a psychotic break (i.e., usually described as a “nervous breakdown”), unable to see all the quirks and foibles of the main characters because they are so common in higher education or science fields, explicitly disabled (like the researcher Kripke with a speech impediment), egomaniacs (or overly dramatic divas), antisocial, or actually physically and visibly disabled (as in the case of Stephen Hawking in a guest role). Although *TBBT* primarily shows academics from science, math and technological fields, even non-scientists at Caltech, like humanities professors who meet Raj and Sheldon at a faculty mixer (“The Psychic Vortex” (3.12)), are still portrayed as geeks (in this case by rocking out with an Xbox and appreciating Green Lantern collectibles).

The only “sane” or “normal” colleagues are usually college administrators like the Dean, who even temporarily fires Sheldon when he accuses the Dean of dumbing down his scientific work (“The Luminous Fish Effect” (1.4)). There are several running jokes about the president of the university putting up with Sheldon as he attempts to solicit donations, participate in public relations campaigns, and follow university policies like taking vacation time.

Students are typically portrayed as sane and normal, usually just barely tolerating professors, who naturally fail to understand students’ perceptions of them. In season four’s “The Thespian Catalyst” (4.14), Sheldon guest lectures for a doctoral seminar in physics. Students tweet that “Dr. Cooper has taken a relatively boring topic and managed to make it completely insufferable. Plus he looks like an insect.” Another asks why time flies when you’re having fun, “but when you’re listening to Dr. Cooper, it falls out of the sky dead?” In an interesting twist, the mad geniuses can even drive students insane, with one student saying that “...Dr. Cooper has made me wanna start cutting myself again.” Yet Sheldon tells his friends that the lecture was “triumphant,” with students “thirsty for knowledge, drinking in my wisdom” and that he “may have changed a few lives.” When Sheldon reads the comments he says they are “rather unfair” and “downright cruel.” “Plus,” he notes, “insects have six legs.” He goes to his room, remarking that he “didn’t want to teach those pooppy heads anyway,” simultaneously dismissing and insulting the students, having an immature tantrum that reinforces students as more mature, and maintaining his status as a genius defining reality in his own delusional but defiant way.

Thus in this fictional portrayal of higher education, these disabilities, impairments, quirks, and even craziness are par for the course among all faculty and researchers – especially those in the STEM fields. Yet part of the humor on *TBBT* is the way it repeatedly forces viewers to question their assumptions about those who seem normal and who is impaired. “Normal” can even be something meriting caution or scorn, while “crazy” ones may be healthy, understanding things most people cannot perceive.

In the second season (“The Bath Gift Hypothesis” [2.11]), the character of Dr. David Underhill is a visiting research physicist in the first season is a MacArthur Genius Award winner who discovers new theories about dark matter; he is an epitome of dark rugged handsomeness and masculinity, riding motorcycles and suavely seducing Penny. Leonard derides this scientist as “a Beauty Queen” who “got lucky.” The “sane” genius is revealed as actually being evil and cruel, heartlessly dumping Penny, who then runs to geeky Leonard for consolation. In another

episode, a 15-year old Asian Sheldon-like genius shows up to become a researcher at Caltech, but gives it up to hang out with girls and teenage peers. Leonard feels guilty for showing him the existence of females and a different life, but Sheldon makes it clear that the boy had a choice and was obviously not genius enough if he chose normality and sex over a life of science and research (“The Jerusalem Duality” [1.12]).

Disability studies scholar Walters (2013), who wrote about autism-related themes and characters in television shows *The Big Bang Theory* and *Community*, speaks favorably about the humor in both series, which also happen to be the only two television series in 2014 that are about higher education:

“Comedies such as *The Big Bang Theory* and *Community* demonstrate [these] characters . . . as essential to social cohesion, and even work to resist the assumption that cognitive difference separates . . . characters into categories of ‘normal’ and ‘abnormal.’ The comic frames of comedies such as these crack the frames of typical instances of disability humor and invent new ways of understanding cognitive differences” (p. 274).

Her comments apply to madness as well as autism, with the show setting up a new cultural media trope of neurodiverse disabled “mad geniuses” as researchers and professors in higher education. While *TBBT* revolves around the apartment of Leonard and Sheldon and was originally designed to be a show about geeks in the normal world, it is clear that their careers infuse their homes and social lives, as well as their interactions with others. The humor for the audience is in recognizing a shared experience or situation (e.g., a fight with a girlfriend), but having it in esoteric science jargon that is sometimes unintelligible even to other characters on the show.

In the second show of the second season (“The Codpiece Typology” [2.2]), Leonard’s girlfriend, Leslie Winkle, argues with Sheldon and is outraged that Leonard won’t stand up for her. While anyone can understand and empathize with the situation, the language is typical science-speak from *TBBT*:

Sheldon (entering living room of apartment where Leonard and Leslie are sitting):
Leonard, you are my friend. And friends support their friends, apparently. So I am withdrawing my objection to your desire to have a relationship with Leslie.

Leonard (to Sheldon): Thank you.

Sheldon: I will graciously overlook the fact that she is an arrogant sub-par scientist, who actually believes loop quantum gravity better unites quantum mechanics with general relativity than does string theory. You kids have fun.

Leslie (to Sheldon): Hang on a second. Loop quantum gravity clearly offers more testable predictions than string theory.

Sheldon: I’m listening. Amuse me.

Leslie: Okay, well, for one thing we expect quanti-space time to manifest itself as minute differences in the speed of light for different colors.

Sheldon: Balderdash. Matter clearly consists of tiny strings.

Leslie (yelling at Leonard): Are you going to let him talk to me like that?

Just as their conversations may be framed as “normal” and “not normal” at the same time, characters’ interactions with each other and their fictional TV community are similarly academic while being relatable to non-academics. The group of researchers hangs out with other geniuses from higher education, whether they are at the comic book store (run by a genius in art who has a degree from the Rhode Island School of Design), or at a paintball competition (where fierce competitors from the geography department use their advanced GPS to defeat colleagues). But eating Chinese food, knowing local small business owners in the neighborhood, or getting competitive with friends and work colleagues are universally understood for viewers in the U.S.

The question for disability scholars is how to deconstruct the humor of *TBBT* and this televised modern version of the academic geeky intelligent “mad geniuses” that are obviously proving popular with mainstream audiences. What implications may they have for disability studies, higher education, and society? For that, I turn to freak show theories and commentary to explain the freak show of *TBBT* as a series, and the freak show of academia as portrayed on the show.

The Freak Show of Higher Education

The complex connections between freaks, geeks, genius, and madness are not unique to the character of Sheldon or other lead characters in *TBBT*. Nerds, geeks, OCD or obsessiveness, and Asperger’s or autism traits are often linked together in the minds of popular culture, the neurodiversity movement, and science research – even when these three groups traditionally agree on little else (Bednarek, 2012; Cefalu, 2009). *TBBT* and the character of Sheldon can be interpreted through disability studies, even though the field has traditionally dealt more with issues of physical embodiment and body criticism, instead of neurodiversity and cognitive freakishness (for examples and critiques, see e.g., Adams, 2001; Bogdan, 1990; Fiedler, 1993; Garland Thomson, 2000; Price, 2011; Wu, 2012).

Since the 1980’s, numerous disability scholars have remarked on the negative portrayals, stereotypes, and tropes of disability in film and television. Disability is often associated with monsters who wreak havoc, murder, terror, and violence (Bogdan, et al., 1982) and it’s quite common for criminals, villains, or general “bad guys” to be easily recognizable by their hunchbacks, grotesque features, or other physical abnormalities, as well as their bitterness or insanity at their lot (rather than their ability to overcome their fate) (Longmore, 1985; Walters, 2013). Sometimes the monsters, like vampires, are even scarier because they look just like us but are eventually shown as the evil freak they really are (McDermott & Daspit, 2005). Disability can also be a “narrative prosthesis” or metaphor representing oddness, collapse, abnormality, or decay (Leuschner, 2006; Walters, 2013). Modern reality TV shows like *Little People*, *Big World* or *Ruby* may even display people with disabilities as freaks, replacing the side

shows of yesterday with more relatable characters and socio-political views of some disabilities, while still giving viewers an opportunity to stare and feel normal (Backstrom, 2012). In fact, despite the many variations in its manifestations, disability in pop culture, film, and literature is ultimately about reproducing, verifying, and justifying all that is normal, sane, and good, because the freak, monster, or deformed humans are compared (and judged) against standards and stereotypes about what is normal in our culture (Titchkosky, 2009).

There is also a close connection between geeks and freaks, particularly in connection with the history of freak shows. In Jon Katz's book *Geeks*, he notes the Merriam-Webster Dictionary's definitions of geeks includes "a person often of an intellectual bent who is disapproved of," with an alternative definition of geek as "a carnival performer often billed as a wild man whose act usually includes biting the head off a live chicken or snake" (p. 5). Katz wryly notes that "definitions involving chicken heads no longer apply" to discussions of geeks (p. 6), but from a disability studies perspective, the historical connection between overlapping worlds of freaks, geeks, and intellectuals is worth noting when Sheldon and other characters on *The Big Bang Theory* so clearly personify all three.

Sheldon and his friends are often described as geeks, and they readily accept and embrace the label. Geeks are usually pasty (and Caucasian), skinny, weak nerds with a near-savant abilities with anything technological. They even relate to others primarily through networks like the Internet or online gaming. Like freaks, they don't have a single culture, but they do have communities and strong connections with each other, and value diverse skills and a responsibility of using those skills for the benefit of humankind. (For further definitions of geeks, see, e.g., Katz, 2000; Kelty, 2005; Postrel, 2010; Quail, 2011; and McFedries, 2008). *TBBT* main characters fit the definition of geek and, as discussed above, they are all mad or disabled to some degree.

This perception of all geniuses as mad is consistent with historical beliefs about mad geniuses, originating in the early 1800's. In his 1978 text *The Mad Genius Controversy: A Study in the Sociology of Deviance*, George Becker analyzed historical interpretations of mad geniuses, showing that essentially only extremely gifted and original thinkers could be gifted enough to be insane. During the Romantic era (end of the 18th century through the mid-19th century), artists, scientists, and writers of genius would even try to associate with clinical madness, testifying to the "marginality" of one's "mental health" and the "frequent deterioration in his mental and physical condition" (p. 64). In other words, the illness proved evidence of the genius. Depending on the viewer's perspective, a mad genius was either "an agent of change and revolution" (p. 109) or "a blessing" and "agent of progress" (p. 111). The difference was dependent on who did the viewing. Becker suggests there was common agreement that geniuses were not normal. If the mind of a genius was not allowed to express itself, be original, and to challenge existing conventions and institutions, then, driven by instincts inherent to genius, it could result in undesirable behaviors, ranging from obscenities and agitation to strange writing and obsession with "minuteness in detail" (p. 112). Some felt that mad geniuses were part of the natural order, and an important part of social change; their contributions to society were to be valued and any seemingly abnormal behaviors tolerated or even celebrated. But others suggested that doctors, psychiatrists, and cultivated educated persons should take over where the criminal justice system could not, imposing social control on those geniuses who showed signs of

madness. Indeed, even in 1978, Becker notes “social control considerations constitute an integral part in the labeling of madness, and, indeed, have figured prominently in the very development of the mental health movement.” (p. 119). Becker’s words are especially chilling in the current climate of U.S. higher education mental health movements, where professionals seek ways to find potentially violent intelligent students and faculty exhibiting any signs of insanity or emotional instability. Indeed, Schumer (2006) noted that historical literary representations of mad scientists and mad geniuses continue to influence the general public’s opinion of science. And even medical professionals and psychiatrists have continued to explore possible biological or genetic connections between various types of mental illness and genius (see, e.g., Johnson, Murray, Fredrickson, Youngstrom, Hinshaw, Malbrancq Bass, Deckersbach, Schooler, and Salloum, 2012; Redfield Jamison, 1993; Weisburg, 1994).

The lead characters of *TBBT* clearly fit Becker’s complex portrait of mad geniuses, driven by their own ultra-intelligent compulsions, free of social conventions, and driven to do original work. Like their Romantic counterparts, Sheldon and his colleagues embrace their “craziness” and intelligence as being intertwined gifts that others may not understand, knowing others may even see them as pathologically different. Borrowing from cultures of freaks and geeks, *TBBT* characters honor each other’s gifts and only use their intellect, scientific knowledge, and technological prowess for good (Katz, 2000; Postrel, 2010), although Sheldon once pondered the fact that many evil villains seem to have doctorates (and his friends have remarked that he is “one lab accident away” from being an evil super villain himself). Even with its casual and frequently ableist banter about neurodiversity and intellectual difference, people put down as “morons” or “stupid” frequently get their chance to show how so-called moronic or stupid the geniuses can be. Penny, Sheldon’s religiously zealous mother, Sheldon’s beautiful but “stupid” sister, and administrators at Caltech are given ample opportunity to outsmart the scientists, show the limitations of their logic and devotion to science, or exercise power over them (sometimes manipulating them by using their own intelligence against them).

The most famous actor to portray mad geniuses was Boris Karloff, whose characters included mad scientists who were blind or wheelchair users, doing evil experiments that put humans at risk (Bogdan et al., 1982). In a more modern take on the role, genius often accompanies OCD or more generic forms of obsession, like Sheldon in *TBBT* or the lead character of television’s series *Monk* who had a label of OCD. These mad geniuses are usually the butt of jokes in sitcoms, where humor and comedy are used to challenge their intelligence, ego, or assumed superiority (Cefalu, 2009). They are often given “childlike” reflexes, an ignorance about their own limitations, and a supposedly comical hyper-awareness of obsessive rituals as problematic but unavoidable (Cefalu, 2009). The comedy comes from them simultaneously not being able to change the limitations they notice, and not realizing how extensive the limitations are (Cefalu, 2009).

Table 2 draws upon works on freaks, geeks, and the “mad genius” scientists featured in *TBBT*, using criteria for each group as defined by Adams (2001), Becker (1978), Bogdan (1988), Bogdan et al. (1982), Fiedler (1993), Garland Thomson (2000), Katz (2000), McFedries (2008), Quail (2011), and Walters (2013). First, the freak show relationship is framed as a triad: the freak/object being viewed; the audience or those doing the viewing; mediators setting up the object and way in which it is viewed, which is traditionally the carny; and (Garland Thomson,

2000). Second, for each to be effective as a freak, the groups have societal or cultural ideals that are challenged or reinforced by the group’s existence. In the case of *TBBT* researchers, societal ideals, normality, and the supposedly normal television viewers are the brunt of the joke (Walters, 2013), whereas freaks and geeks are often portrayed in ways that reiterate the status quo of their freakishness and the viewers’ normality, healthiness, and beauty. Third, each group has rituals, ceremonies, props, language and jargon to not only signify who is an insider or outsider, but to solidify community, norms, and the boundaries of the group. As Adams describes, “Freak is not an inherent quality, but an identity realized through gesture, costume, and staging” (2001). Lastly, each has a domain where the freak show occurs, from stage shows to the Internet, or science labs.

Table 2. This is a comparison of freaks, geeks, mad geniuses, and characters on ‘The Big Bang Theory,’ based on descriptions of each group in Adams (2001), Becker (1978), Bogdan (1988), Bogdan et al. (1982), Fiedler (1993), Garland Thomson (2000), Katz (2000), McFedries (2008), Quail (2011), and Walters (2013).

<u>Freak Show Traits</u>	<u>Freaks</u>	<u>Geeks</u>	<u>Mad Geniuses/ Mad Scientists</u>	<u>The Big Bang Theory’s Geeky “Mad Geniuses” Freaks</u>
Object/viewer/mediator triad	Freak/spectator/carnie or ringmaster	Geek/suits, non-geeks, or non-techies/Internet	Extreme intelligence that is potentially dangerous/people of normal intelligence/the monsters, evil, or ill-conceived experiments showing their madness	Genius researchers and professors/television audience/sitcom format, <i>TBBT</i> writers and producers
Ideal challenged or reinforced by group	Beauty, normality	Anti-intellectualism, neurotypical cognition, social convention, nerd vs. cool or hip, athleticism	Science, evolution, technology	Difference, normality, intelligence
Rituals, ceremonies, icons, staging, props, and discourse	Examples: language of “carnies” and “rubes,” pageantry and showmanship of	Examples: pocket protectors, sickly or weak appearance, skills with	Examples: Lab equipment, books, evil laughter, esoteric science jargon, separateness and	Examples: lack of social skills, out-of-fashion or geeky attire, use of science and pop culture references to explain

	sideshows, costumes and spectacles (like marriages of little people for show)	technology, jargon-speak, obsession with pop culture, social interaction mediated by technology and Internet	alienation from normal people (e.g., the tower on the hill away from the villagers), lack of ethics in the name of scientific progress	daily social interactions, appearance of work items and language at home (and vice versa), abnormal sexual behavior, habits revolving around science fiction, gaming, and comics, reverence for all things related to hard sciences and technology
Inhabited domains	Visual mediums, including stage, photography, reality television	The Internet; any obsession (e.g., music geek, gaming geek, crafty geek)	The science lab, technology	Higher education; technology; geeky activities like comics, gaming, and paintball; on a literal level, the sitcom format of <i>TBBT</i>

In the case of *TBBT*, it is particularly interesting to note two levels of freak shows. In one case, the viewer is *TBBT* audiences, watching a fictional freak show involving Sheldon and others. The second freak show is the fictionalized world of higher education inhabited by Sheldon and other lead characters. In this world, Sheldon and other academics are portrayed as freaks that are only normalized by being in an academic environment where their personality, cognitive, and physical traits are typical or tolerated for the sake of their work. This is consistent with observations by Bogdan (1988), who observed that freak shows were often set up like human service agencies, with “presentation and profit” by nondisabled people being in the forefront, while real disabled people were behind the scenes (p. 279). In the case of *TBBT*, disabled academics do the work, while institutions of higher education run by seemingly nondisabled administrators profit from their labor.

TBBT's humor about the freakdom of geeks, mad geniuses, and academia are often less than nuanced and they frequently problematic for disability scholars. *TBBT* may be contributing to the emergence of “geek chic” (Quail, 2011, pp. 466-467), but its humor often relies on oppressive racial, gendered, and sexual norms about geeks for the jokes to be funny, just as nerd or geek identity is often created in response to oppressive societal ideals of hip, cool, normal, masculinity, or corporate (Quail, 2011). For example, *TBBT* may have Raj, an Indian geek with brown skin, but the rest of the scientists and researchers follow sociocultural constructions of geeks who tend to be pasty white, educated, and middle-class enough to afford the technology that forms a foundation for their community (Quail, 2011). There is also no question that the “mad genius” of *TBBT* scientists alludes to stereotypes in place since Dr. Frankenstein of the 1800's. Even as the geniuses are now working out of apartments in California, in many ways

they are still metaphorically holed up with eccentric assistants (or colleagues) in an Ivory Tower, using science that may be advanced, but is also unintelligible and bordering on dangerous (Becker, 1978).

The issue of madness, OCD, or mental disability being connected to genius and academia is also troublesome for the way society views cognitive neurodiversity, including intellectual disabilities, mental disabilities or mental illnesses, and those with dyslexia or brain injuries (Price, 2011; Becker, 1978). On *TBBT*, characters frequently use the terms “idiot,” “moron,” or “stupid” as socially acceptable epithets that don’t bear further scrutiny or criticism. People with seemingly average intellect (like Penny) are portrayed as hopelessly stupid at times, and people with intellectual disabilities have never appeared on the show; for all intents and purposes, this entire population is non-existent in *TBBT*’s universe.

Other disabilities are also fodder for jokes, even when characters get in trouble for it. When Raj dated a Deaf woman and his friends suspected she was after his money, Penny remarked that it couldn’t be true because “handicapped people are always nice” (although it was, in fact, completely true) (“The Wiggly Finger Catalyst” [5.4]). When dating, Raj and Howard would often count on lawyers and accountants to “thin the herd” at bars, hoping to pick up the “blind and fat chicks” left over. The joke was that the two guys never actually left with any women, including the disabled ones, so the disabled women apparently had higher standards or social standing than the men suspected. There are frequent references to Howard’s mother being fat, mimicking of Stephen Hawking’s computerized voice, and jokes about other disabilities that come up on the show. Like the rest of *TBBT* humor, it walks a fine line between offensive and transformative, offending people, allowing characters to get in trouble for their comments or beliefs later, but then re-offending to start the cycle again. It relies on dated beliefs and language about disability, while simultaneously allowing the lead characters to have disabilities that are progressively accommodated without question. This framework of incongruity takes the different or “out of place” and transforms it, making it more dynamic or deliberately contradicting it both conservative and progressive viewers are uncertain what is really appropriate, normal, different or out of place after all (Walters, 2013, p. 272). And with the evolving nature of *TBBT* characters, everyone is allowed to learn from their mistakes. By its nature, television shows are intimate, with interactions between characters and interactions between characters and the audience, as viewers “meet” characters in their homes and grow with them over time (Bednarek, 2012). The subtleties of *TBBT* may resonate with viewers who worry about offending someone or being politically incorrect in a complex multicultural society.

Indeed, *TBBT* may be viewed as crippling the concept of “spread effect,” a term from psychology and rehabilitation that describes how a single disability or perceived disability can eclipse all other characteristics of a person in a negative way (e.g., assuming a physical disability indicates a lack of intelligence) (as originally developed by Dumbo, Leviton, & Wright, 1956 and Wright, 1983). But instead of difference or disability “spreading” and negatively stigmatizing every aspect of characters (for discussion, see, e.g., Longmore, 1985), the disabilities, impairments, and differences in *TBBT* are a part of each character, evolving and affecting each other’s development, with the “spread effect” being interpersonal and frequently positive. As it moves into its seventh season, viewers have seen Sheldon pull together an awkward hug and a couple of kisses for Amy, Howard has grown up a bit as a married man,

Penny has found her inner geek on occasion and tried college again, Leonard seems to be sustaining his relationship with Penny (possibly into marriage), and Raj is now able to speak in front of women.

There is a myth in geek folklore that says the Internet is so dynamic and ever-changing that it has decentralized routing protocols that can withstand any damage, including a nuclear attack; if anyone tries to limit or censor the Internet it will be perceived as damage, and the tech will route around it (Kelty, 2005). Like this myth, it seems *TBBT* has evolved to “route around” any efforts to normalize it; the producers have quickly realized that the most alienated character of Sheldon is the most beloved, that adding more science only enhances the show, and that a reverence for geekdom is a secret to success with audiences despite a U.S. climate of pervasive anti-intellectualism that often features resentment against academics (Cross, 2005; Leuschner, 2006; Postrel, 2010; Sheffield, 2010; Tucker, 2010). If *TBBT* characters are a complex new generation of geeky disabled mad geniuses, re-interpreting and frequently crippling stereotypes of freaks, geeks, and madness, as well as impairment, disability, and difference, then the next logical question is what the *TBBT*'s portrayal of academics and the freak show of higher education may teach society about higher education and disability.

The Perpetual Spotlights of the Academic Freak Show

Margaret Price wrote *Mad at School* (Price, 2011), a critique of higher education concepts like rationality through a disability studies lens rooted in rhetoric related to mental disabilities, mental health, and mental illness. She further examines requirements of faculty and students in academia, including what she calls “kairoitic space,” the informal, implicit, and usually unnoticed spaces of higher education where knowledge and power are created and reinforced (Price, 2011, p. 60). Her examples include interactions in hallways, at meetings, during conferences, and even supposedly informal events like parties or other social events for faculty and students.

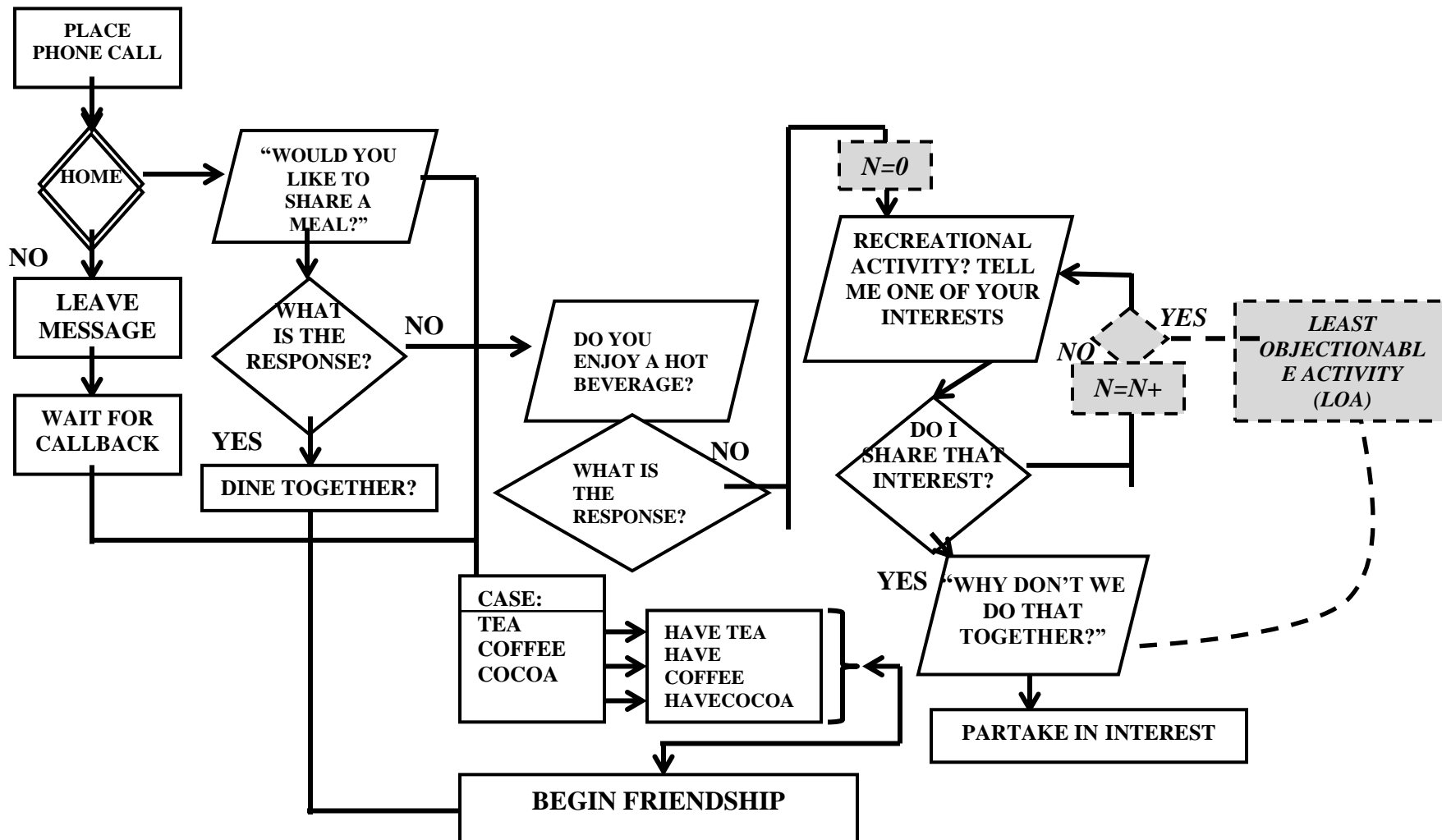
TBBT rarely shows researchers trying to teach anything or engage in any sort of mentoring, pedagogical work, or efforts to improve their teaching. Instead, nearly every episode is about their social interactions, sex, dating, hobbies, and a steady diet of take-out food. Yet this fictionalized account of academic life aligns with the real world of academics and Price's definition of kairoitic space, where distinctions between work, home, and relationships are blurred. There are white boards full of theorems in *TBBT* living rooms, paintball games against professorial foes from other academic departments, carpooling games like ranking famous scientists, and the use of logic and research to make sense of illogical social norms. There is rarely a time when any of the scholars on *TBBT* “turn off” any part of their mad genius. They aren't only “mad geniuses” at work, or *TBBT* would take place on campus. The characters are mad geniuses all the time – that's why it's entertaining, why it resonates with real scientists and professors, and why they're mad.

The lives of academics are portrayed as a 24-hour, 7-days-a-week role – a freak show with spotlights that shine continuously at home, work, and in the community. *TBBT* builds this idea of a perpetual freak show through the characters being disabled, the characters being in the literal spotlight of a television series, and through the content and plot lines reiterating the

unchanging message of non-stop academic life, geekiness, and mad genius to viewers (despite evolutions in other aspects of the characters' lives). Here Price's work and *TBBT* converge: if academics are mad genius geeky freaks, and higher education is the freak show where they perform; the kairotic space of academia means they are never really out of the spotlight or their role as freaks.

The way characters accommodate each other is very similar to relationships of freak show performers, as well. Sideshow freaks and geeks supported each other and formed a family or community that often existed even after they retired (Adams, 2001; Bogdan, 1988). The academic characters on *TBBT* have a similarly close bond, forged in their experiences of being different (all of them, for example, have mentioned experiences being bullied as children). They also frequently accommodate each other by negotiating in the moment as peers, doing what many professionals in disability-related fields call "natural supports." Unlike real-life academics with disabilities, the main characters are never isolated (except by choice), and they do not need to seek out a disability services office to get accommodations. Many episodes feature the group trying to figure out simple things like how to attend the Renaissance Fair or a movie while accommodating all of the group's complex needs, with the needs of Sheldon often being the most complex and therefore the most challenging to negotiate. When Sheldon becomes sick, for example, the friends implement a formal protocol for dealing with him (or avoiding him) and for also supporting Leonard as Sheldon's roommate ("The Pancake Batter Anomaly" [1.11]). In "The Friendship Algorithm" (2.13), Sheldon uses a children's how-to-make friends book about Stu the Cockatoo (who was new at the zoo) to create a flow-chart algorithm for making friends (see Figure 1). It begins with "Place Phone Call," and ends with "Begin Friendship" or "Partake in Interest" options, using logic decision trees like "Do You Enjoy a Hot Beverage?" where "Yes" leads to suggestions of having tea, coffee, or cocoa, and "No" leads to suggesting a recreational activity. Sheldon gets stuck in an infinite loop when he objects to all possible activities potential friend Kripke is suggesting. Howard solves the problem by fixing the chart with a loop counter and an escape to the least objectionable activity. He fixes the problem by adjusting the chart, not by assuming it will not work for Sheldon or that Sheldon is incapable of friendship. Sheldon is then able to move forward with the least objectionable activity, and planning a day out with a potential new friend.

Figure 1. Sheldon Cooper's algorithm for making friends, from "The Friendship Algorithm" (2.13), with grey boxes indicating Howard's loop counter and an escape to the least objectionable activity.



But while Sheldon's need for supports and assistance could become a troubling punch line if it was always one way, he is not the only one who needs them. *TBBT* has shown viewers the extent to which Sheldon sometimes accommodates his friends and colleagues, even if others do not notice it. When his three male friends head for Vegas, Sheldon delights in plans for a quiet evening at home with non-Kosher Indian food full of dairy, noting that the absence of Jewish Howard, Indian friend Raj who hates Indian food, and lactose intolerant Leonard have freed him up to do as he wishes ("The Vegas Renormalization" [2.21]). Until that time, it wasn't clear to viewers or other characters that Sheldon's complex schedules and timetables for meals might be considering his friends' needs and wishes, as well as his own.

Sometimes the supports and accommodations become the central focus or running gag within an episode. When Raj dated a Deaf woman, he was not mute and could talk to her (because she could never hear him). But polyglot Howard had to interpret communications into ASL, and Raj had to learn limited sign language, leading to several humorous situations when Howard was distracted, preoccupied, or figuring out so-called better ways to phrase things, and not interpreting everything accurately or completely ("The Wiggly Finger Catalyst" [5.4]).

This particular aspect of *TBBT* is consistent with progressive disability politics, which seek ways to adjust the environment rather than forcing the disabled person to overcome a disability, hide it, or adjust to an environment that creates impairment. Indeed, for many disabled academics and students, *TBBT* represents a sort of universally designed utopia where accommodations may occur without typical formal arrangements, inconveniences, justifications, concerns about costs, approval letters from professionals, and disability documentation usually involved in getting the most basic of services. All the main characters "speak the same language and respect each others' boundaries" (Sheffield, 2010, p. 26). When things aren't perfect, everyone tries to work through it together. *TBBT* characters might be teased by others, but there will always be something to tease back about, too. Academics (especially scientists) with disabilities are taken seriously for their work, because none of them look good, they are all intelligent, and all of them are disabled in some way; their disabilities are not a way to distinguish them from other academics. Even the viewer is also metaphorically disabled upon entering their world, needing accommodations just to understand much of the science jargon – Penny frequently stands in for the viewer as the "disabled" one who misses science fiction, comic, academic, or science references, puzzling that the academics are so clueless about "American Idol" or keeping up to date with the social lives of Hollywood stars. But even Penny needs accommodations, adjustments, and assistive technologies to succeed and thrive (the men are her live tech support, and the women often act as her interpreters, explaining jokes or jargon, and offering advice). Indeed, all of the accommodations on *TBBT* are perpetual and organic, and there is no expectation that the accommodations will cease or fade out (a common professional euphemism for gradually removing people's accommodations in the seemingly hope that they will become unnecessary, regardless of what disabled individuals may want or need).

When people are not acting like their usual selves on *TBBT*, others may remark that it's too weird, creepy, or even crazy when they are acting "normal." In "The Itchy Brain

Simulation” (7.8), Sheldon at one point promises to “not freak out” when Leonard discovers an overdue videotape due seven years before. Sheldon actually doesn’t freak out, and Penny has to leave the room because she can’t stand to watch Sheldon reacting calmly to something that would normally upset him; acting normal is freaky, and freaky is normal.

At the same time, the constant supporting and accommodating again reinforce Price’s notion of kairotic spaces. *TBBT* characters accommodate mad genius academics on campus or at home, because they are always acting out of their primary identification as a scientist or researcher. But this never-ending academic existence and dedication to one’s field is problematic for real-life faculty with disabilities, who are trying to negotiate tenure processes, high-speed publish-or-perish mentalities, and political hierarchies of campuses. In reality, academia is not a welcoming place for most graduate students and instructors with disabilities, and many feel the need to hide their disabilities (or aspects of their disabilities) while negotiating for every accommodation (Bell, 2007; Franke, Bérubé, O’Neill, & Kurland, 2012; Hockman, 2010; Solis, 2009; Valle, Solis, Volpitta, & Connor, 2004; Vance, 2007; White, 2008). In fact, 75 percent of campus disability services offices are set up to serve students, but not faculty or staff (Fuecker & Harbour, 2011; Harbour, 2004). For real-life disabled academic freaks or those who actually carry a disability label associated with “madness,” *TBBT*’s messages might be familiar, funny, and oppressive, all at the same time: you are indeed a freak, administrators and students will most likely think you’re abnormal, the only accommodations will be the ones you get from other freaks/colleagues, and there will never be a break or respite from demands of your 24/7 academic life.

The humor with Sheldon and other *TBBT* characters resonates with many scientists and academics because they are wrestling with shared frustrations of publishing, research, administration, teaching, etc. But the humor sends complicated messages about links between intellectualism and madness, genius and geekiness, and being at the mercy of colleagues who are creative or tolerant enough to deal with the foibles of your disabilities or difference. In the real world of higher education, where all the professors do not have disabilities and the ones who do are marginalized for it, the progressive and entertaining humor of *TBBT* may seem wry and hollow (for further discussion of faculty with disabilities, see, e.g., Franke, et al., 2012; Fuecker & Harbour, 2011; Michalko, 2001; Vance, 2007; White, 2008).

Meanwhile, college students watching *TBBT* are learning explicit and implicit messages about their professors being extremely intelligent but also potential mad geniuses – especially those in the scientific fields. Nondisabled faculty may get a skewed picture of the disability experience in higher education, where ableism is minimized and disabled colleagues are part of a comedic spectrum of quirkiness in faculty. Disabled undergraduates and graduate students who dream of being researchers or professors learn that once you choose those careers, there is no escape from the spectacle of academic life. The only consolation, perhaps, is that you might be surrounded by people as freaky as you. The only way to survive the freak show is to support each other, embrace your freakiness, and ignore any illusions that normal ever existed in the first place – mixed messages indeed.

Conclusion

This paper has discussed how *TBBT*, especially the character of Sheldon, tests new boundaries and definitions for a modern version of the geeky mad genius, living in the non-stop freak show of academic life. The show utilizes problematic, oppressive, and ableist societal norms and pop culture tropes to make Sheldon and his mad genius colleague relatable and familiar. At the same time, it questions, challenges, and contradicts these assumptions while allowing characters to evolve over time and accommodate each other's needs, providing a way for general audiences to begin thinking about neurodiversity and societally constructed definitions of normality.

Very little research has been done on disability and higher education, or images of disability and higher education in pop culture and the media. It would be valuable to examine other television shows and movies where higher education is utilized in some way, to see what themes and messages about disability are present. Previous research (e.g., Dagaz and Harger, 2011) have used social science methodology to examine whether images of higher education may affect college student behavior or attitudes; these could be replicated to consider images of disability in higher education, as well.

In addition, *TBBT* shows no signs of waning popularity. As it continues to garner critical acclaim, large audiences, and national awards, it is likely to stay on the air for quite some time. Disability scholars may wish to look at other facets of this show, including intersections between disability, race, gender, and other facets of characters. Likewise, this article focuses primarily on the researchers and academics of *TBBT*, but “non-academic” characters also portray disability or ambiguous impairments, and disability is a frequent comedic foil.

Until there is scholarship about various aspects of disability and higher education, disability in its many forms will continue to be invisible, underestimated, or even suppressed in academia (Anderson, 2006). Likewise, until connections are made between pop culture images of disability in higher education and experiences of people living and working on campuses, we will not fully understand how disability is constructed in postsecondary education, or how disability is fully experienced by disabled and nondisabled students, faculty, and staff. *TBBT* presents complicated narratives and messages about disability and higher education; disability studies and higher education scholars have an opportunity to interpret this in new directions, complementing and critiquing the humor in a way that befits our pride and power, as disabled people, geeks, mad geniuses, and freaks.

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Best Practices in Disability Studies

Not Just Academic: How Sociologists and Anthropologists Promoted Inclusion in the Community for Individuals with Disabilities

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Abstract: My aim in this essay is to renew interest among new generations of leaders in the field in the contribution of Erving Goffman and his disciples to understanding their impact on the promotion of inclusion in the community for individuals with disabilities. Goffman's focus on interaction, where identities are arrived at, or where strong status differences establishes identities, was a foundation for disability studies and the development of new policies contributing to the transformation of government-directed program responses to disabilities in the second half of the twentieth century in many countries. I follow this remarkable change in approach via the work of sociologists and anthropologists who adopted Goffman's conceptualization of total institutions and stigma, through to contemporary studies of inclusion.

Keywords: Goffman, Disability, Sociology

Until the 1970's, the practice of placing people with intellectual and developmental disabilities (IDD) in large and isolated settings was regarded as both humane and legally correct. Then, some community-based voluntary associations sought legal redress for patterns of abuse, neglect and deprivation in such facilities. A noted challenge to keeping individuals with IDD in state schools is found in *Halderman v. Pennhurst State School & Hospital*, 446 F. Supp. 1295 (E.D. Pa., 1977). This litigation encouraged the development of new community options and the close of facilities in a number of states.

It may be hard for students in disability studies programs to understand how American society could simply put away this population. Nevertheless, separation and isolation was the public policy in all the states, with these qualities considered to be a way of making society a better place and a form of protection for those who could not fully take care of themselves.

A reversal of thinking and practice took place. As in the *Pennhurst* decision, courts often upheld the rights of individuals with IDD who lived in large and isolated state schools, also known as asylums, to active treatment and return to the community. The practice of "warehousing," as it became known, was replaced by new policies of community care. Reformers in the United States learned about established humane policies and practices in the United Kingdom and the Scandinavian countries that could serve as models for change (Wolfensberg, 1969; Kushlick, 1975; Tizard, 1964, Kugel and Wolfensberger, 1969).

Change in disability practice came from diverse sources, including social science concepts and research. My aim in this essay is to renew interest among new generations of leaders in the field in the contribution of sociologist Erving Goffman and his disciples to the understanding of how the self emerges via social interaction. His dramaturgical, or performance-based approach to the study of social situations and how society is constructed is useful for

understanding how the self emerges. For budding sociologists interested in answering the big question, “How is social order maintained, modified or dissolved?,” Goffman’s work was inspiring. His concepts were readily applied to the study of disability starting in the 1960’s.

Goffman's focus on interaction, where identities are arrived at, or where strong status differences establish identities, was a foundation for disability studies and the development of new policies contributing to the transformation of American and European government-directed program responses to disabilities in the second half of the twentieth century.

The most profound changes in response came with regard to people with IDD, who had often been removed from the dangers of society, as well as to limit parental burdens. While some scholarly observers may regard the change in thinking about services for people with IDD as an evolutionary process, starting with the politics of the civil rights movement and the subsequent actions of families seeking better care and advocating for educational programs for their children, the new approach came from conceptualization that questioned the widely held Social Darwinian beliefs that the "normal" should be freed from the burden of caring for the "mentally retarded" in the community, and that the "mentally retarded" should be protected by living in restricted settings.

Not everyone supported this approach. Some parents worried about whether their children could survive in a less protected environment. Some parents did not want their adult children with IDD living either at home or in community residences because they chose not to reveal their existence to their colleagues or neighbors. In addition, some professionals, who had a vested interest in keeping state institutions open, opposed community care.

The Theoretical Model for the Study of Total Institutions

Following the end of World War II, a number of diaries and memoirs of people who were incarcerated in European concentration camps and prison-of-war camps were studied closely by sociologists and anthropologists to determine the impact on the self of these experiences.

Criticism of American mental hospitals by psychiatrists and psychologists emerged in the 1950s and prompted participant observation studies of these facilities by sociologists and anthropologists. Erving Goffman adopted a role as a participant observer within a mental hospital in Washington, D.C. to study how behavior was influenced by organizational constraints and opportunities, and wrote about it in his classic study, *Asylums*. The way the self is constructed by the environment became central to understanding human development and interaction.

In turn, Goffman was very influential on later generations of sociologists and anthropologists who explored what happens when former inmates are returned to the community and live in group homes and other settings. Goffman’s brilliant work on “total institutions” continues to resonate more than a half century after it was published. In the following quote, Goffman identifies characteristics of total institutions:

“Every institution captures something of the time and interests of its members and provides something of a world for them; in brief, every institution has encompassing tendencies. When we review the different institutions in Western society, we find some that are encompassing to a degree discontinuously greater than the ones next in line. Their encompassing or total character is symbolized by the barriers to social intercourse with the outside and to departure that is often built right into the physical plant, such as locked doors, high walls, barbed wire, cliffs, water, forests, or moors. These establishments I am calling total institutions, and it is their general character I want to explore” (Goffman, 1961, p.4).

In the 1970's, when large and isolated institutions were being closed because the quality of care was poor, and residents, often known to the employees of these programs as "inmates," were being resettled in the community, Goffman's intellectual leadership was recognized by sociologists such as Sam Seiffer and myself. In our monograph, *Resettling Mentally Retarded Adults in a Managed Community*, we studied what happened when people with IDD were returned to community settings. We reported on the process and outcome of this major shift in public policy in Goffman's language. Court decisions, while setting in motion deinstitutionalization, did not capture the transformations that were anticipated when return to the community took place.

The meaning of social institutions and their impact on the way we live and particularly on those who are considered incapable of caring for themselves may be illuminated by the findings reported here. Special-purpose organizations have often been given complete control over the fate of large numbers of persons deemed incapable of caring for themselves and/or thought to be a danger to themselves and others. Central to such “caretaker” organizations are three tasks: (1) the need to maintain internal order and coordination; (2) continued reaffirmation of the rightness of the initial judgments made about persons designated as convicts, mental patients, and residents (some of the popular labels applied to inmates); and (3) safeguarding the public from the inmates. Sometimes it may be conceived that such organizations through their practices, confirm the need for their existence by calling forth in their wards evidence of “personal maladjustment” and “social incompetency.” Alternatively, sheer neglect and under-stimulation may produce behaviors which are regarded as bizarre and inappropriate but may, in actuality, be the only possible way for inmates to express their unfulfilled needs. Organizationally, these behaviors operate in a self-serving and self-fulfilling way to justify the need for tight control over inmates' lives (Birenbaum & Seiffer, 1976, p.6).

From Total Institutions to Stigma

In *Asylums*, Goffman examined a variety of settings he characterized as total institutions, including many where mental patients and other inmates lived. Coming out of a total institution left a mark on former inmates, and sometimes, after release into the community, they preferred not to disclose where they had been. In other words, former patients as well as ex-convicts, regarded this information about themselves as potentially stigmatizing. Managing information about their history was a way to avoid being considered less than fully deserving of respect. Sociologists, under Goffman's influence, began to recognize the importance of "the other" in determining one's behavior and how social identity is shaped.

Origins of the Concept of Stigma

New encounters were based on social diversity. With ethnic and racial minorities migrating to northern cities during and after World War II to take jobs in an expanding economy, social scientists saw opportunities to study what happens when minority group members come into the presence of dominant, or "ordinary," people. Diaries and memoirs published by people with physical disabilities described the indignities to which they were subjected by "normals," who treated them as less than fully human. Along a similar path, those people with IDD who were not living in large and isolated state schools, received more education than in the past and in the community they had more contact with "normals." In some states, such as California, some long-term residents of state schools were deemed capable of taking care of themselves and were returned to the communities where they were born.

Preliminary Conceptions

Goffman taught us that social reality was made through interaction. An individual's identity was a product of the information he or she gave off when in contact with others and therefore it established the right to be present in an encounter. Early on in *Stigma*, Goffman lays out the rules related to social identity: "Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for members of each of these categories. Social settings establish the categories of persons likely to be encountered there (Goffman, 1963, p. 2). But what happens when individuals are regarded as not fitting in?

"The term stigma, then, will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed. An attribute that stigmatizes one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself" (p. 3).

An individual who does not measure up in a particular situation, and now is regarded as "the other," has to come up with a strategy to deal with this differentness in face-to-face interaction:

"The term stigma and its synonyms conceal a double perspective: does the stigmatized individual assume his differentness is known about already or is evident on the spot, or does he assume it is neither known about by those present nor immediately perceivable by them. In the first case one deals with the plight of the discredited, in the second with that of the discreditable" (p. 4).

From the perspective of the person who is doing the stigmatizing, i.e., the "normal," there are concerns about how to characterize this social inferior. Sometimes there is an existing set of expressions available to facilitate the categorization of someone as a social inferior:

"By definition, of course, we believe the person with a stigma is not quite human. . . . We construct a stigma theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as social class. We use specific stigma terms such as cripple, bastard, moron in our

daily discourse as a source of metaphor and imagery, typically without giving thought to the original meaning” (p. 5).

Once Goffman establishes the structural parameters of his interests in writing *Stigma*, he reveals his focus: "The issue of 'mixed contacts'—the moments when stigmatized and normal are in the same 'social situation,' that is, in one another's immediate physical presence, whether in a conversation-like encounter or in the mere co-presence of an unfocused gathering" (p. 12).

There may be tension or at least awkwardness in these encounters. Every transgression of these norms in the form of a discrediting discrepancy between an actor's expected and actual identity calls into question the validity of these rules because those who cannot sustain competency may still seek to do so. The everyday grounds for judging others and oneself are made problematic because actors are uncertain about the kinds of claims that may be made by both the discrepant and the conventional individuals.

These "primal scenes" of social life are often filled with embarrassment, awkwardness, and confusion. Generated by gaps between the way things are anticipated and the way they turn out, such encounters between discrepant and conventional individuals need to be made routine in order to end uncertainty on many levels. The discrepant person needs to be defined in a permanent way to end the discrepancy to organized social life. Once society's designated agents redefine the discrepant person as being outside the conventional social order, the everyday grounds for the judgment of social identities are confirmed, thereby restoring belief of all members of society in the cultural formula they have learned to follow. Moreover, the removal of uncertainty allows the stigmatized person to continue his or her membership in the social order, albeit assigned to a radically different master status.

The Stigma of Disability in Everyday Life

If we start with individuals possessing the social skills of any member of society, despite the acquisition of a disability, that may limit performing the tasks of daily life, calls into question one's right to be treated as an equal. Acquiring a disability, or becoming a "significant other" of someone with a disability, involves a new social identity. Adaptation to this new fact about oneself is complicated by its social consequences or stigmatizing impact--what amounts to having a spoiled identity. A fully competent social actor, has to learn how to deal with a diminished social status and play an unwanted role. The acquisition of a disability equals the acquisition of a stigma—the individual is seen by others, and is often seen by him- or herself, as being tarnished or spoiled.

Confirming the impact of stigma beyond disability itself is evident in the personal experience of social anthropologist Robert Murphy, who acquired a severe disability in midlife. He viewed the linkage between physical difference and social stigma this way:

“Disablement is at one and the same time a condition of the body and an aspect of societal identity—a process set in motion by somatic causes but given definition and meaning by society. It is permanently a social state. . . .The onset of quadriplegia, I discovered, had placed me in a new social dimension” (Murphy, 1987, p.195).

Stigma acquisition is also a form of downward social mobility as Murphy explains. People who cannot fully do basic things for themselves and who are perceived as not able to do for others cannot take part in a fundamental ritual of social life in any society—the principles of reciprocity, as identified by the French anthropologist, Claude Levi-Strauss (1969), almost 50 years ago.

The more conformist the culture, the more people with disabilities are shunned, their families are embarrassed by their presence, and little effort is made to accommodate people with physical limitations. In contemporary Japan—one of the most modern and developed societies technologically—individuals with disabilities "are often discouraged from working, from marrying, from going to movie theaters or restaurants." (Kristof, 1996) In comparison, countries like Sweden, Denmark, and even the United States, appear willing to promote the civil rights of people with handicapping conditions, even when full acceptance by others may not take place.

Acquiring a disability, or becoming a "significant other" of someone with a disability, involves a new social identity. Taking off from Goffman, I note that the problem of stigma is a problem of everyday existence for the bearer. He dealt with the following questions: (1) What does it mean to play a stigmatized role in society? and (2) Why do people who are considered imperfect continue to act competently?

People with disabilities, despite their differentness, can take the role of the other. Being a fully competent member of society includes recognizing the meaning of membership and competency. This reflexiveness or being able to take the role of the other, involves knowing what a member must possess and who is allowed to participate in particular social situations. Alternatively, knowledge of what it means not to be a member is part of the general role of the member. These rules or constitutive norms of social life are acquired relatively early in life.

Encounters between discrepant and conventional individuals are made routine in order to end uncertainty on many levels; the discrepant person needs to be defined in a permanent way to end the disruptions to organized social life. Society is protected when designated agents redefine the discrepant person as being outside the conventional social order; beliefs of all members of society in the cultural formulas they have learned to follow are restored. Harold Garfinkel (1956), a contemporary of Goffman, regarded these rituals as "degradation ceremonies."

Moreover, the removal of uncertainty through these rituals allows the stigmatized person to continue his or her membership in the social order, albeit assigned to a radically different master status. Once an individual acquires a disvalued identity, later encounters in his or her life as a stigmatized person acquire a predictable quality (Schutz, 1962).

Novelist and literary critic Leonard Kriegel regards the presence of disability much in the same way as Alfred Schutz, but also as a barrier to being validated as a person. In his powerful autobiographical account, Kriegel presents the other as failing to recognize the self present in the person with a disability. Note that he avoids the use of softer language when referring to his situation:

“What the cripple must face is being pigeonholed by the smug. Once his behavior is assumed from the fact that he is a cripple, it doesn't matter whether he is viewed a holy or damned. Either assumption is made at the expense of his individuality, his ability to say "I." He is expected to behave in such-and-such a way; he is expected to react in the following manner to the following stimulus. And since that which expects such behavior is that which provides the stimulus, his behavior is all too often Pavlovian. He reacts as he is expected to react because he does not really accept the idea that he can react in any other way. Once he accepts, however unconsciously, the image of self that his society presents him, then the guidelines for his behavior are clear and consistent” (Kriegel, 1969, p.424).

When we examine childhood-onset disability, as was the case in Leonard Kriegel's life, the focus has largely been from the perspective of how families cope with stress. When a child becomes disabled, or is recognized as such at a young age, families invoke common-sense understandings related to the causes of the disability, hold different expectations concerning the child's survival, and make judgments as to what success, or lack of it, this child will have in school, work and family life. Not unexpectedly, the family now is engaged in a multi-member career as a group with a disabled member (Groce & Zola, 1993).

A family's culture supports the interpretations and problem-solving efforts brought about by the presence of a child with a disability; it is also the force behind the coping strategies they adopt. The family's unique character is derived from deeply held beliefs and values, what Hamilton I. McCubbin and his co-authors (1993) called a family schema. With this cultural foundation, often based on ethnic values, the family develops a set of guidance mechanisms (paradigms) that steer their behaviors and functioning.

Courtesy Stigma and Parents of Children with Intellectual and Developmental Disabilities

While the concept of stigma in the field of disability usually applies to individuals with disabilities, it is also used to gain greater understanding of those who are underdogs because of their relationships to fully stigmatized individuals.

In my early work, I followed the social relationships of mothers of young children with IDD and found that they too were seen as having a spoiled identity, or what Goffman called a courtesy stigma. First published in *The Journal of Health and Social Behavior* in 1970, my article "On Managing a Courtesy Stigma," was republished twice and often cited during the following four decades. The idea of a courtesy stigma has been applied to other family members, such as siblings and to group home workers and neighbors of individuals with intellectual and developmental disabilities (Birenbaum, 1970). More recently, the concept has also been applied to parents of adolescents who are heavy drug users.

Goffman's Influence on Anthropology

Around the same time, using the concept of stigma, Robert B. Edgerton, an anthropologist, initiated a community-based study of several "mildly retarded" adults who were released from state schools. His monograph, *The Cloak of Competence*, was considered a

pioneering effort at urban field work. Using a very loosely structured interview schedule and participant observation, Edgerton became part of the lives of his subjects. He brilliantly focused on "the perception and management of incompetence—stupidity if you will—among the mildly retarded" (Edgerton, p. 6). Edgerton learned about their lives in the institutions or state schools they had come from, and also about their current concerns. This study, "Beyond its possible merits as a description of the lives of such folk, . . . is also intended to be a study of a stigma, a stigma which galvanizes the most basic feelings of these retarded persons into a single-minded effort to 'pass' and to 'deny' "(p. 205).

The Cloak of Competence uses succinct quotes from these former patients in order to get at the sense of stigma they were facing:

Woman: "When I got out of this place it was horrible. I knew everybody was looking at me and it was true what they thought I was.

Man: "I don't believe that anyone from the hospital has it easy outside. There are problems from being in that place. I mean with people you meet. They take me as if I am not a smart person" (p. 206).

The struggle to command respect involves avoiding being seen as a person with a disability. In the efforts of the former patients in the present study to evade the stigma that they feel and fear, we see an eloquent testament to man's determination to maintain his self-esteem in the face of overwhelming cultural rejection and deprecation (p. 219).

Direct Applications of Stigma Theory to Practice in the Intellectual and Developmental Disability Field

Stigma theory moved beyond academia and helped shape human service policy and practices in several countries in Western Europe in the 1960s. While Wolf Wolfensberger, a German-born policy maker in the Swedish social services system, held an advanced degree in psychology, his approach to human services was basically sociological. In *The Principle of Normalization in Human Services*, he defined human management as the "entry of individuals or agencies acting in societal-sanctioned capacities, into the functioning spheres of individuals, families, or larger social systems in order to maintain or change conditions with the intent of benefiting such individuals, their family or other social systems, or society in general" (1972, p. 2).

The idea of normalization is directly related to Goffman's concept of stigma and mixed with famous American sociologist Robert K. Merton's self-fulfilling prophecy (a concept now used regularly on cable channel news broadcasts). Normalization implies that a person would be enabled to project an image that does not mark him as deviant in the sight of others. The rationale for this is twofold. First, as stated, how a person is perceived affects the way he is treated, and a person seen as deviant is very apt to elicit pity, rejection, persecution, and other behaviors which tend to diminish a person's dignity, adjustment, growth, etc. Secondly, the way a person is treated by others will affect his self-image, as well as the way in which he will respond. It is well known that a person perceived to be deviant is expected to act with deviance,

and such expectations are often so powerful as to elicit the expected behavior, thus becoming self-fulfilling prophecies (Wolfensberger, 1972, p. 229). Normalization, according to Wolfensberger, "Can be viewed as being most consistent with a sociotherapeutic approach in that it uses concepts and constructs rooted primarily in sociology, and does so at a time at which the field appears to be ready to orient itself increasingly toward sociotherapeutic concepts" (p. 103). Inspired by international conferences of adults with IDD in Sweden in 1968 and 1970, Wolfensberger and his colleagues moved toward the concept of self-determination. The focus on leisure time activities generated a preference for participation in small groups, whether in public or in smaller settings. The idea of self-determination was born through discussions regarding programs and programming (p. 184). The strong opinions held by the people with intellectual disabilities on their right to take part in decisions regarding their own leisure time activities reflect their dissatisfaction with situations they have so often experienced when things have been arranged for them and not with them, thus increasing their feeling of dependency and depriving them of a part of the pleasure of motivation (p. 185).

Further Use of Sociological Theory and Methodology to Improve Services for People with Disabilities

By the late 1960s, the social environment and cultural disadvantages experienced by people with developmental disabilities was becoming a major concern to government policy makers since the environment in which this population lived was changing. Adults with intellectual and developmental disabilities were now viewed as much a product of their environment (large and isolated institutions) and the stigmatization experienced by being separated from mainstream society.

Resettlement was not deemed enough of a public policy solution to promoting inclusion. Residential care in group homes often consisted of being in the community but not of it. It also became apparent in this decade of emerging civil rights that individuals, whether coming from their homes or resettled back in the communities where they were born from the traditional state school, often needed to be taught the skills required for community living. Understanding how social organization impacted the development of the self when there are differences in intellectual capacity became something that sociologists could untangle, often with the help of other academic disciplines.

Based on a conference sponsored by the National Institute for Child Health and Human Development and the Rose F. Kennedy Center for Research in Mental Retardation and Human Development at Albert Einstein College of Medicine, *The Mentally Retarded and Society* contains 22 major articles by leading specialists in intellectual disabilities and human development, psychology, psychiatry, sociology, mental health, developmental disabilities, pediatrics, maternal and child health, education, public health, education, law, anthropology and epidemiology (Begab and Richardson, 1975). (One of the attendees was Erving Goffman, who acted as a gadfly and did not contribute a paper.)

Following in the footsteps of Edgerton, the conference featured the policy study of the consequences for adults with intellectual disabilities who move from a large, traditional, isolated mental retardation institution to smaller residential care units in the community. Noting the

importance of the civil rights movement, organized citizen groups, professional societies and human rights-minded attorneys, editor Michael Begab suggests that these agents of change have “embarked on aggressive campaigns of public education and class action suits to secure for the retarded the basic rights presumably guaranteed by our Constitution. In the process, old concepts such as community integration of the retarded and normalization have been rejuvenated” (1975, p. xi).

The Fields of Vocational and Physical Rehabilitation as Subjects for Sociological Study

The road to inclusion for all people with disabilities, including those with IDD, often involves partnerships between federal agencies and social scientists. In response to what was deemed the “dramatic and frightening growth of dependency” on the part of people with disabilities on public assistance, the Commissioner of the U.S. Vocational Rehabilitation Administration, Mary E. Switzer, challenged the discipline of Sociology to come up with “something special” that could help alleviate the mounting burden on public funding. Writing in 1965 in the introduction to *Sociology and Rehabilitation*, Commissioner Switzer noted that people with disabilities were seen as deviants and therefore stigmatized by the larger society (p. viii). These “deviants,” according to Switzer, were made up of both those with physical and nonphysical disabilities, including “the mentally ill and the mentally retarded.” Consequently, they were treated as unworthy of being included in the larger society and incapable of making a contribution to it.

Clearly, Erving Goffman's conceptualization regarding spoiled identities hovered over the proceedings where academics were seeking to guide policy formation in the field of rehabilitation. At the conference sponsored by the Vocational Rehabilitation Administration, most of the papers presented began with the acknowledgement that the stigmatization of people with disabilities has a long tradition in western societies and rooted in their cultures. Social stigma, according to Jerome Myers (p.37), one of the presenters at this conference, was rooted in the classification system of people with different disabilities and their acceptance in social situations. Social distance has often led to the creation of subcultures and communities among those who are similarly situated.

While not specifically addressing the problems of integrating people with IDD into the workforce, almost 50 years ago the American Sociological Association, in cooperation with the Vocational Rehabilitation Administration, held a conference where distinguished sociologists presented and critiqued six foundation papers that linked sociological theory and research to the conditions under which rehabilitation was successful. These papers, which were published by the American Sociological Association in 1965 in *Sociology and Rehabilitation*, a volume edited by Marvin B. Sussman, looked at how disability could be defined in terms of the social stigma attached to it as well as “the degree of social isolation of the disabled person, the amount of role impairment, or the theory of causation of disability” (Jerome K. Meyers, p. 37).

Meyers also notes that one of the consequences of disability “is the promotion of a higher degree of interaction among the disabled than would otherwise occur. In a sense, the disabled frequently develop subcultures or communities of their own. This tendency for disabled persons

to seek social satisfaction with each other has produced a complex system of social organization” (p. 41).

Continuing in the Goffmanian tradition, Eliot Freidson, in his essay in *Sociology and Rehabilitation*, introduces the conceptualization of disability as social deviance in his discussion of rehabilitation, and systematically identifies what activities the rehabilitation field conducts. First, they specify what personal attributes shall be called “handicaps.” Second, they seek to identify who conforms to their specifications. Third, they attempt to gain access to those whom they call “handicapped.” And fourth, they try to get those to whom they gain access to change their behavior as to conform more closely to what the institutions believe are their potentialities (p. 71).

The Corporate World of Rehabilitation

While the concepts of total institutions and stigma were powerful applications of sociology to the world of the other, more sociological approaches to disability and rehabilitation emerged, largely due to the emergence of the recognition of the need for intervention on a scaled-up level. The sheer growth of the field of rehabilitation has produced interests that go beyond face-to-face interaction. Few subjects in the area of disability studies are more controversial than whether rehabilitation empowers individuals to make improvements or, on the other hand, subjects them to a new kind of stigma. At issue today is how to help individuals with disabilities make the transition from sheltered workshops and occupational day programs into either competitive or supportive employment.

Many vested interests in the rehabilitation field depend on keeping clients in programs that restrict their opportunity for independence and inclusion. Advocates for people with disabilities often point to how vocational rehabilitation facilities discourage their trainees from seeking more challenging employment. Fueled in the United States by the infusion of funding from federal and state agencies and some insurance programs, rehabilitation has become a complex process, one that begins with limitations in an individual’s functional activities.

This enormous world of rehabilitation starts, once again, with an individual’s differentness. The differences in a person’s life as a result of a disability impact on the way roles are performed and how one acts in social situations. As sociologist Gary Albrecht (1992) observes, “Persons with disabilities discover that their social activities and by analogy their social identities are redefined by the attributions assigned to the disability with which they have been labeled. These labels and stereotypes often inaccurately reflect the behavioral capacity and identity experienced by persons with disabilities. As a consequence, persons with disabilities may try to take the definitional process into their own hands” (p. 18). Starting from a Marxist or materialist perspective, and examining who controls the means of production in rehabilitation, Albrecht identifies the commodification of the field. These rehabilitation “goods and services are commodities that are marketed, sold and purchased. In such a market, consumers, providers, investors, and regulators profit and/or lose in the transactions” (p. 27).

How can these forces be resisted or reshaped? Albrecht speaks to empowerment as coming from people with disabilities and /or those with a deep humanitarian devotion to the cause. The two necessary elements of leadership empowerment are self-awareness and the

acquisition of resources to act on their own behalf (p. 311). Self-advocacy can be a solution for creating greater equity when people with different disabilities are able to form alliances. Paradoxically, the recognition of stigma promotes solidarity and calls for a remedy to the social inferiority experienced by people with disabilities.

The most powerful response to these structural conditions is likely to be exerted through a national coalition formed by different disability interest groups. Such a coalition can be organized to achieve strong lobbying but preserve the identity of the member organizations (p. 314).

Inclusion: Continued Research on Community Living by People with IDD

With the closing of large and isolated state schools in many countries, policy makers and planners have expressed concern about how to promote integration of individuals with IDD in ordinary neighborhoods. Resettlement continues to take place in the Netherlands as recently as the last decade. What factors in social contact promote integration at the neighborhood level?

To answer this question, a study of a neighborhood with group homes in the Netherlands started with 53 potential informants, and eventually learned about neighboring experiences from 39 people with IDD, ranging from superficial neighboring to the formalization of relationships with some non-IDD neighbors. As the authors state:

“There seemed a preference for social contacts to be with other people with ID, family and volunteers, rather than people from outside the context of the organization” (Van Alphen, et. al., 2009, p. 753).

Accordingly, staff of the organization that ran the group home were active in setting guidelines for how residents should behave when in the presence of neighbors. Residents were grateful for this help. As noted in other articles by the same team of researchers:

“There may . . . be a certain insecurity to approach others because past experiences have taught some people to be wary, or if they do not feel competent enough, and think that their disability may frustrate interactions” (p. 755).

The Dutch team of sociologists then spoke with 30 neighbors near these group homes to get their impressions of the people with IDD who lived in several resident facilities. These “normals” expressed concern about the often-noted lack of appropriate distance, reciprocity and accountability among their neighbors with IDD. Inclusion can be difficult to attain when neighbors are involved:

“Integration of people with IDD into everyday neighboring relationships raises complex challenges for care organizations that need to find a balance between supporting the needs of people with IDD they care for, adequate support and mediation for other neighbors when necessary, and all the while avoid becoming overly involved in neighboring as a formal partner” (Van Alphen, et. al., 210, p. 347).

The authors identified as a theme the need to try to strike a balance between ordinary neighboring and being mindful of the special needs and challenges presented by their neighbors with IDD, including understanding that their neighbors may be pressed to become more involved than intended. Fear of becoming a benefactor—as addressed by Edgerton in *The Cloak of Competency*—was an unspoken concern.

Finally, the article outlines some theoretical and practical implications for inclusion, such as how staff are required to take into account the insecurity of residents when meeting unfamiliar others, the need to pass on an understanding of local customs, and how to teach what are the possible roles people with IDD can play as good neighbors, with the aim of establishing mutually acceptable forms of neighboring.

Conclusion

Without empirical evidence, but with years of observational experience, I find it likely that generations of students who went into the field of services for people with disabilities were moved by reading Goffman, or perhaps some of his disciples, as undergraduates or graduate students in sociology, social-psychology, or social work. These opportunities for learning a nuanced approach to disability helped to create more quality service providers than in the past. The numbers of young people who went into this field expanded with the proliferation of community care.

The idea of capacity-building, a concept often found as part of the mission of organizations funded to improve the quality of care in the disability field, along with systems change and advocacy, especially self-advocacy, rests largely on being able to take the role of the other even when the experiences of the other are very remote from a person with training. The enduring impact of sociology on the study of disability, policy formation, and planning remains evident in the twenty-first century.

Arnold Birenbaum has been the Associate Director of the Rose F. Kennedy University Center for Excellence in developmental disabilities at Albert Einstein College of Medicine and a professor of pediatrics for the past 20 years.

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Multimedia Reviews

Book Review

Title: *Ed Roberts: Father of Disability Rights*

Author: Diana Pastora Carson; Drawings by Patrick Wm. Connally

Publisher: Indianapolis, IN: Dog Ear Publishing 2013

Paperback: ISBN: 978-1-4575-1952-9

Cost: \$14.95, 30 pages

Reviewer: Steven E. Brown, Ph.D.

For many years I have anticipated the day Ed Roberts would be taught in history textbooks, just like James Meredith, who broke the American university color barrier for college students in Mississippi in 1962. That same year Ed Roberts provided a similar breakthrough for students with significant, or high-level, disabilities, at the University of California at Berkeley.

This book, targeted at elementary school-age children is long overdue. Clearly written, with a lot of blank spaces on a few pages, Carson's style is direct and to the point. I wanted to know a little more about the intended audience, so wrote the author. She quickly and cordially replied:

“Ed's work had some high-level concepts and vocabulary that were difficult to translate into a format for younger audiences. I recognize that the language level in the book varies. But given the Common Core Standards, at least in my district, teachers are now supposed to provide rigor and scaffolding in instruction, including high level vocabulary and challenging concepts” (Personal correspondence, Feb. 28 2014).

While aspects of his life are missing, such as his marriage, divorce, and fathering of a son, I recognize the Ed I knew and became friends with in his later years, and the focus is on his role as “Father of Disability Rights.” (In full disclosure, I have also written about Ed--see References). Ed possessed an uncanny ability to connect with pretty much everyone he encountered. He frequently showed up late for meetings because he would spot someone with a disability on the street and, especially, if he did not know them, would stop to talk with them because he wanted to encourage them to engage.

As a person with a significant disability--using a respirator to breathe during the day, an iron lung at night--he rarely traveled anywhere alone. One of his frequent companions was Patrick Wm. Connally, a colleague and artist, whose magnificent drawings on the book cover and opposite each page of text, which some readers might find far less direct than Carson's writing, I believe both reflect and enhance the text.

The book begins when Ed is described as, “fourteen when it suddenly seemed that he would never go to college, get a job or get married” (p. 2) because he became disabled from polio. But he did do all of these things, and much more. Ed attended and taught college, married, had a son and at one of his jobs, became Director of the California Department of Rehabilitation, after having been told by a worker at that same agency he was too disabled to ever work.

Ed also co-founded the public policy think tank, the World Institute on Disability, received numerous awards, and traveled around the world. When he died in 1995, many people traveled to Berkeley, (including my wife and me) to celebrate his life. Carson concludes, Ed, “proved that people with disabilities can work and play together with everyone else” (p. 30).

This book can be used as a model for addressing disability rights biographies and issues for younger audiences. It not only belongs in every school library; more importantly, it belongs in a range of curricula.

Steven E. Brown is the co-founder of the Institute on Disability Culture (<http://web.mac.com/disculture/>), a poet, essayist, and speaker. A collection of essays, *Movie Stars and Sensuous Scars: Essays on the Journey from Disability Shame to Disability Pride* is available at many online bookstores. He may be contacted at: sebrown@hawaii.edu.

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Book Review

Title: *Accessible Citizenships: Disability, Nation, and the Cultural Politics of Greater Mexico*

Author: Julie Averil Minich

Publication Data: Philadelphia, PA: Temple University Press, 2014

Softcover: ISBN: 978-1-4399-1070-2; also available as an e-book

Cost: \$26.95, 240 pages

Reviewer: Donna McDonald, Ph.D.

An (un)holy trinity: Chicana/o cultural representations of the politics of disability images
The title of Minich's book—*Accessible Citizenships: Disability, Nation, and the Cultural Politics of Greater Mexico*—led me to believe that it would take up the challenge of the late Chis Bell's lament that disability studies fails to engage with issues of race and ethnicity (2006). As a lecturer of disability studies in Australia, I was keen to be illuminated about the indigenization of disability in Greater Mexico, with a view to extrapolating the themes of this book to other cultures. Unfortunately, while Minich's book responds to Bell's challenge, I was disappointed.

Minich's ambitions for her book—"My focus on disability and Chicanismo as sources of important insights about nationalism and citizenship stems from a belief in the political value of subaltern or minoritized identities" (p. 5)—are wide-reaching, but teasingly obscure to apprehend. Her analysis of representations of disability in contemporary Chicana/o literature and film as a way of understanding political engagement requires a deeply shared commitment by the reader to her task for two important reasons. First, Minich's selection of Chicana/o novels and films to illustrate her arguments assumes that both the Chicana/o and non-Chicana/o readers will be familiar with those cultural texts. This hurdle could be reasonably accommodated but for the second (and more fatal) obstacle: Minich's opening essay—"Accessibility and Nationalism: An Introduction" (pp. 2-27)—plunges the reader immediately into her complex, layered, and circumlocutory theoretical propositions, instead of providing a clear, concise description of the role and purpose of each of the following chapters. Without such a map, the two hurdles combined to make this particular reader anxious about how to make sense of the entire book. It also left me none the wiser about the day-to-day realities of contemporary disability politics in Greater Mexico.

Given that Minich makes much of her "scholarship" in her "Acknowledgements"—she notes that "no scholarship is the work of one person alone" (p. ix), that this is her "first scholarly book" (p. ix), and she thanks "scholarly organizations" (p. xi) for their support—it appears that Minich considers other scholars to be her target readers. Indeed, Minich stakes out her narrow readership territory on page 2: "disability scholars ... [scholars of] political belonging including Chicana/o studies, border studies, and queer studies". However, this select readership for Minich's indisputably solid piece of research will need significant prior knowledge of the cultural and literary texts which Minich explores to support her thesis. Alternatively, they need to

be prepared to Google-search them during the course of their reading. Certainly, few readers outside Greater Mexico are likely to be at home with the works of “gay Chicano writer . . . with disabilities” Arturo Islas Jr. (p. 32), “feminist playwright, poet, and queer theorist Cherrie L Moraga” (p. 57), “the younger Chicana queer writer Felicia Luna Lemus” (p. 57), “Alex Espinoza—a gay, disabled writer who identifies as both Mexican and Chicano (p. 95), Oscar Casares, Chicano writer and film-maker (p. 124), and Chicana novelists Ana Castillo and Cecile Pineda (p. 156). (Tommy Lee Jones is a rare familiar celebrity name in Minich’s exposition. He gets a fleeting mention as a “white, Anglo actor-director” (p. 124) who collaborated on Casares’s film “The Three Burials of Melquiades Estrada”).

Further, the strenuousness of Minich’s thesis—that Chicana/o literary culture conceptualizes the political community through images of disability—is hard to shake off. While sincerely argued, her expository style occasionally feels contrived, convoluted and jargon-heavy. Examples can be found in any chapter, for example:

“*The Rain God* and *Migrant Souls* counter normative narratives of Chicana/o family; instead of positing the patriarchal family as an idealized representation of the nation, they reveal the violence and trauma that must be edited out of the family history in order for the patriarchal family to present itself as a whole and unified representation of the whole and unified nation” (p. 55).

This could be distilled to, “Contrary to idealized images of Chicana/o patriarchal families (symbolic representatives of a whole and unified nation), *The Rain God* and *Migrant Souls* reveal the hidden violence and trauma in Chicana/o families.” Another example the reader has to step her way through:

“I have scrutinized the liberatory potential (and shortcomings) of queer cultural nationalisms. These next two chapters, on the other hand, are concerned with dominant, state-supported nationalism—and more specifically, with the ways in which US nativism reinforces an exclusionary construction of the US national body that is mobilized to justify brutal immigration restrictions” (p. 95).

So much is contained in these 53 words. It is too much to absorb in a single reading, and requires the reader to slow down and parse each phrase before moving to the next phrase.

Having said this, Minich undeniably makes a unique and substantial contribution to our knowledge. Indeed, it is the hallmark of a fine scholar to make known what has been unknown, unfamiliar and formerly unreachable. This is how our understanding of humanity expands. Minich’s commitment to this challenge can be seen in her every attentively crafted sentence, every conceptualized paragraph, and every narratively shaped chapter. For this reason alone, Minich’s book is of substantial benefit to disabilities studies.

Minich states that her book “began with my dissertation research at Stanford University” (p. ix). This goes some way to explaining the complexity and density of her writing: the power of her ideas is often overwhelmed by the weight of her concepts. It would take a determined scholar to read her book from “go-to-whoa”. However, that determination would reap rich rewards for a

disability studies or political studies scholar. A reasonably priced book, it would also be a good addition to the “required reading list” for a graduate class on disability studies, political studies or the humanities, providing a suitably provocative counter-weight to the usual suspects of white disability studies texts.

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Book Review

Title: *Autism: A Social and Medical History*

Author: Mitzi Waltz

Publisher: New York: Palgrave Macmillan, www.palgrave.com, 2013.

Hardcover: ISBN 978-0-230-52750-8

Cost: \$85.00, 188 pages

Reviewer: Mark Romoser

As I write this, several Autistic people are at the White House, participating in its first-ever forum on LGBT (Lesbian, Gay, Bi-Sexual, Transgender) disability issues. In *Autism: A Social and Medical History*, Mitzi Waltz shows us just how unlikely this would have seemed, even a decade or two ago, and what a long journey it has been for them and their forebears.

To a large extent, the history of autism is intertwined with that of mental illness, and of neurological diseases, such as epilepsy. In fact, the word “autism” was not used until 1943, by Dr. Leo Kanner at Johns Hopkins University. Walsh has done a remarkable job of going through older case histories from as far back as 18th century Scotland and finding those of people who today would meet diagnostic criteria for autism. She analyzes a broad range of religious and folk beliefs that have been applied to Autistic people, such as “changelings”, children who were supposedly stolen by fairies or demons. Similar rhetoric is used today, for example by practitioners of methodologies such as Applied Behavior Analysis, who might say something like, “Act now or you will lose your child forever!”

Since 1943, the emphasis has shifted to finding the cause(s) of autism, and in many cases, a cure. By its very nature, autism is difficult to study in detail. This has led to some bizarre theories of causation over the years. Walsh comes to grips with the controversy surrounding Bruno Bettelheim and his “refrigerator mother” theory, which posits that autism is caused by mothers paying insufficient attention to their infants (pp. 73-75).

The first organizations devoted to the study of autism, such as the National Autistic Society (NAS) in the United Kingdom and the Autism Society of America in the United States (US), were composed solely of medical professionals and family members of Autistic people, leaving no voice of their own to Autistic people. Only recently has this balance begun to shift. Walsh chronicles how the NAS has become more inclusive of Autistic people, and how they have formed their own organization in the US, the Autistic Self-Advocacy Network (ASAN). (Disclaimer: The reviewer is a regional contact person for ASAN.)

This is a valuable work for any collection concerned with autism, or with disability history. Autism obviously did not spring into existence full-blown in 1943, but very little other work in the field reflects that. Several attempts have been made to place Sherlock Holmes on the

autism spectrum, but that is hardly edifying (Frith, 1989). Walsh takes things a large step further by dealing with real people from the 18th century to the present day.

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Mark Romoser was diagnosed with autism at the age of 4, by the renowned Dr. Leo Kanner. After attending eight different schools and two colleges, he became a *cum laude* graduate of Yale in 1985. Mark has worked with top researchers in the autism field, including Dr. Fred Volkmar at Yale. Most recently, Mark has been employed at Silicon Valley Center for Independent Living, in San Jose, California, as a community advocate. Mark has presented on his personal experience with autism for over twenty years. He may be contacted at: markr@svilc.org.

Notes from the Field

The 1994-1995 National Health Interview Survey on Disability (NHIS-D): A Bibliography of 20 Years of Research

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Abstract: The 1994-1995 National Health Interview Survey on Disability (NHIS-D) has been one of the most unique and important data sources for studying disability, impairment, and health in the United States. In celebration of the NHIS-D's twenty-year anniversary, we created an extensive bibliography (n=212) of research that has used these data.

Key Words: National Center for Health Statistics; National Health Interview Survey on Disability; NHIS-D

In the 1990s, the United States implemented the Americans with Disabilities Act (ADA) and other policies to deter discrimination against persons with various types of disabilities (Hendershot, Larson, & Lakin, 2003). An outcome of these policies was that both private businesses and public organizations were met with new requirements to increase accessibility and fair treatment of individuals with disabilities. As with the implementation of any new policy, the need for quantitative data to monitor the effects of these policies, and the resulting experiences of the individuals they impact, became apparent. With no readily-available dataset to meet these needs, four U.S. Federal agencies collaborated to design and implement a nationally-representative survey. The end result was a survey supplement that accompanied the 1994-1995 National Health Interview Survey (NHIS), referred to as the National Health Interview Survey on Disability (NHIS-D) (Hendershot et al., 2003; Simpson, Keer, & Cynamon, 1992).

Over the past twenty years there have been numerous sources of data used to study disability, impairment, and health in the United States. However, of these data sources the NHIS-D has arguably been one of the most unique and important. First, it contains a variety of measures that can be used as indicators of impairment and functional and role limitations (Altman & Rasch, 2003). Second, with multiple agencies involved in determining its content, its data covers a wide array of topics that can be empirically examined. Finally, it is also a nationally-representative dataset that allows broad generalization, and generalization to more specific subpopulations (e.g., children with special health care needs, families with a member who has a disability). While the NHIS-D also has its limitations (Altman & Rasch, 2003), these have not outweighed its strengths. As evidence of its importance, peer-reviewed research that uses the NHIS-D is still being published, and the National Center for Health Statistics (the agency that conducted the NHIS-D) still receives questions and comments from its data users

inquiring if and when another version of the NHIS-D will be designed and implemented. Although another version has not been implemented, in response to what has been learned from the NHIS-D a number of survey questions asking respondents about impairment and limitations have since been added to the NHIS and are included annually on the survey.

In celebration of the NHIS-D's twenty-year anniversary, we created an extensive bibliography that is comprised of research that has used these data. The purpose of this bibliography was to not only serve as a resource for those wishing to identify studies that have used data from the NHIS-D, but also document the vast amount of knowledge the field of disability studies has gained through this survey supplement.

We constructed this bibliography by conducting a systematic literature search that identified manuscripts which utilized, discussed, and/or analyzed data from the NHIS-D. Nine terms were used as keywords in the search, which included: (1) National Health Interview Survey on Disability, (2) NHIS-D, (3) NHIS on Disability, (4) National Health Interview Survey Disability Supplement, (5) NHIS Disability Supplement, (6) National Health Interview Survey Disability Followback, (7) NHIS Disability Followback, (8) National Health Interview Survey Disability Component, and (9) NHIS Disability Component. Both the terms *National Health Interview Survey Disability Followback* and *NHIS Disability Followback* were also searched using the two alternative spellings: "Follow Back" and "Follow-back." Searches for these keywords were performed in three databases (Google Scholar, PubMed, and Web of Science) for the years 1990-2013, and concluded in January 2014. Although the NHIS-D was not conducted until 1994, the preceding four years were included in the search to ensure any manuscripts published on the methodology, planning, and/or implementation of the NHIS-D were captured.

Our search yielded 256 manuscripts that were initially identified as having used the NHIS-D. The types of manuscripts included were books, book chapters, peer-reviewed journal articles, brief and full-length research reports, doctoral dissertations and master's theses, and conference proceedings. We omitted any abstracts from conferences that appeared in our search results which were not part of a complete proceedings paper. Each of these manuscripts was subsequently obtained and reviewed in detail, and any study that did not utilize, discuss, and/or analyze the NHIS-D data was removed (44 manuscripts).

The final result of our literature search was a total of 212 manuscripts that were included in the proceeding bibliography. As the NHIS-D was designed to ask questions on a broad range of topics, the focus of these manuscripts encompass research on numerous subjects including (but not limited to) the use of assistive devices, work/employment and disability, children with special health care needs (CSHCN), caregiving, the relation of chronic conditions and disability, access to care and service utilization by individuals with disabilities, and even survey methodology. Collectively, this large number of manuscripts, and the plethora of topics they investigate, exhibits the sustained usefulness of the NHIS-D over the past twenty years and the vast amount of knowledge that has been added to the field of disability studies by this survey supplement. We hope this extensive bibliography will encourage researchers to continue to use the NHIS-D and its resulting publications to generate new knowledge that may further advance our understanding of disability and impairment.

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