

Chapter 98

I Stand with Henry: A Case Study of An Advocacy Organization's Use of Social Media – How a Grassroots Organization Can Have a Voice in a Large Public Bureaucracy

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ABSTRACT

This study investigates a virtual ad-hoc organization known as “I Stand With Henry” (ISWH). It features an individual middle school student with autism practicing self-advocacy. His mission is to support inclusion and get his school district to sanction his ability to be included in the general education setting instead of a separate school for students with special needs. While ISWH is not an official not-for-profit organization, it performs similar functions. Through an in-depth analysis of the ISWH Facebook page, virtual ad-hoc organizations redefine what it means to be a not-for-profit organization. This study analyzes how social media gives voice to the voiceless and how social media equalizes marginalized voices for all students with disabilities to exercise their rights. The chapter employs analysis of conversations within a single case to construct a virtual advocacy model that explains the success of ISWH.

INTRODUCTION

I Stand With Henry (ISWH) is a virtual ad-hoc organization (VAO) which began on Facebook in September 2012. It depicts the struggles and ultimate success of Henry Frost, a student with autism and self-advocate, who wants to be included in the traditional middle school curriculum rather than attend a school that segregates school age children identified as “exceptional.” It begins with a picture of Henry holding a sign related to his self-advocacy efforts to attend his neighborhood middle school. The school

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is identified as Wilson school, situated in Hillsborough County School District (HCSD), the 8th largest school district in the nation, which includes Tampa, Florida, and its surrounding municipalities.

Henry has been designated as a student in HCSD's Exceptional Student Education (ESE) program. Some students with Individual Educational Plans (IEPs) are included in the regular classroom while others are segregated in programs that only serve students with disabilities. The ISWH postings provide a timeline and account of the bureaucratic process that Henry goes through to make changes related to exceptional student designation (Loutzenhiser, 2014). Followers of this page learn immediately that public education decision-making is a lengthy and bureaucratic process. While the chapter includes discussion on inclusion, it does not address the full scope of the inclusion movement. The goal of the chapter is to glean insights related to the strategies and tactics that can make an individual or a small group successful in influencing the decision-making of large bureaucratic institutions via social media applications and techniques.

Who Is Henry?

The mission of ISWH is to protect and support the right of ALL kids including those with disabilities to be able to access schools in their immediate neighborhood. Henry, along with his family and friends, put information on the pages. The Facebook page represents Henry as a self-advocate who asserts that all students, including those with autism, have a right to equal access to public education in their immediate communities. The ISWH organization represents the process of inclusion through an account of a middle school boy with autism. Henry is authentic and credible because he has an experiential understanding of autism and what he wants for his education. He does not believe that the services that HCSD offers outside of his neighborhood school provide a better alternative for what he needs. He asserts that he wants to be treated like "a person" and shares his convictions with a wider audience. The human rights oriented message is shared through status updates that educate, inform and call people to action. Henry's story is told through pictures, videos, calls for action, and interactive discussions. The dialogic communication on ISWH works to build relationships with members of the ISWH community. The authenticity of Henry and his support systems invites attracts and engages more people thus building and strengthening a social capital on the page.

THE ROLE OF TRUST IN BUILDING RELATIONSHIPS

This sections explains strategies used in Henry's case to mobilize and attract many followers. Trust increases the likelihood of people wanting to share and exchange information on Henry's page. There is a caption on one post, for example, that says, "this is not just my fight. Things will not change, if they just change for me." (October 12, 2012). The ISWH page offers a place for people to exchange stories about their similar school experiences. The page reflects a vulnerability, trust, support and compassion that make his story powerful. For example, when asked what he is missing about the general education experience, Henry responds simply: "everything" (October 29, 2012, ISWH). On September 20, ISWH posts a news article that states that Henry will be able to attend Wilson Middle School. The following sections look at the methods that were used to hold the school district accountable. ISWH is an example of social media facilitating the role of whistle blowers in addition to providing an example for small VAOs (Heath, 1997).

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