

## **Virtual Organizational Development and the History of the Internet: A Case Study of Parallel Evolution**

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### **Abstract**

*Online support communities and grass roots organizations have met since the 1990s via a milieu often advantageous to both. While the numbers of such virtual organizations appear to be growing, there is little published research on the historical encounter of a population in need with the internet driven development of a non-profit which addresses those needs. This article examines the organizational development of the International Paruresis Association as parallel to key advances in the technology of the internet.*

**KEYWORDS:** online support community, paruresis, anxiety disorder, social phobia; virtual organizational development, case study

### **Introduction**

Online support groups arose in the 1990s and have attained near global use. From the initially cost prohibitive possession of government and business alone, personal computers are now widely available in homes, schools and public libraries. Internet access can be as immediate and portable as a notebook or cell phone. Advancements in computer technology, affordability and accessibility converged with a social hunger for rapid and sometimes anonymous communication with like minded or similarly situated others. Thus, E-communities exist for a panoply of human interests and needs. These can be as varied as hobbyists; members of a profession; trauma survivors; political party affiliates; charity fund raisers; cohorts based on education, geography, familial ties or shared service; and people with medical or mental health diagnoses (Goldstrom et al., 2006; Wiederhold, 2000). Research began appearing in the 1990s on how virtual communities function, the populations they address, and their relation to social capital and to identity formation (Gibson et al., 2000; Kraut et al., 1998a ; Lin, 2001; Wellman, 2001). Apprehension was variously shared by government, business, and individuals about the potential for loss of privacy, breach of personal information, data insecurity, misinformation, social isolation and exploitation of vulnerable populations ( Kraut et al.,1998b; Nie, 2001; Schopler et al.,1998).

Technological advances and several longitudinal studies helped mitigate some of these concerns (Bessiere et al., 2010; Bonetti et al., 2010; Pfeil et al., 2011; Ritterband, 2006; Valkenburg & Peter, 2009) . The present study builds on the important work of Jones & Meier (2011) whose case study of [www.parentsofsuicide.com](http://www.parentsofsuicide.com) provided an historical assessment of an e-community and had access to its unpublished documents, group members and leaders. The present study similarly operates from an historical outlook, uses unpublished documents, and accesses the group leader. But its uniqueness in the published literature lies in examining not only how a mental health population turned to the internet for support, but how key advances in internet technology paralleled the formation and development of an organization founded to address that population's needs.

## **REVIEW OF THE LITERATURE**

### **Key Developments in the History of the Internet**

Identifying recent and scholarly monographs for a chronology of internet development proved surprisingly difficult. The present study drew upon a 3 volume work edited by Poole (2005): The Internet: a historical encyclopedia. Also, data on internet usage, analysis and trends have been reliably presented since 2000 by the Pew Internet Project, an initiative of the non-profit Pew Research Center ([www.pewinternet.org](http://www.pewinternet.org)). Because the organization that is the object of our case study dates its founding to the mid-1990s, computer and internet developments from that time are emphasized here, with some background history required.

Key changes occurred in the 1980s. Newsgroups, run by a moderator, enabled access to interests organized topically (e.g., religion; sociology). Domain Server Names (such as ...ourtown.com) were easier to remember than Internet Protocol numbers (such as 12.34.56.78). Dedicated workstations (prior to desktop PCs) became connected by a local area network rather than by a cable. By 1990, telephone dial-up access to connect to the internet was commercially available through world.std.com (Poole, 2005; White, 2005).

The early 1990s saw the internet, computers, and computer usage transformed. From the initial province of a tech savvy or well funded few, anyone with a computer and a connection could access the same website and the same information. The new document format called Hyper-Text Markup Language (HTML) and Hyper-Text Language Transfer Protocol (HTTP) expanded multimedia capacity (Mowery & Simcoe, 2002). Keyword searching became possible via search engines such as Archie or Veronica. The World Wide Web enabled HTTP to distribute collections of hyper linked information to users anywhere in the world.

In 1992, there were 4,000 newsgroups and, for the first time, U.S. law permitted commercial traffic on the internet. By 1995, online dial-up systems such as AOL and Compuserve began selling internet access and email accounts to individuals. Intel released a 133 MHz processor. In 1996, hotmail offered free email accounts as an alternative to the commercial products. Through the end of the 1990s, domain names were bought and sold to businesses wanting an easily remembered web address. Yahoo became a search engine and web portal; Google came online as a search engine; and advances in encryption technology enabled Paypal in 1998 to provide electronic financial transactions via the internet. By 2000, over half of U.S. households had internet access, and Intel released a 1.13 GHz processor (Poole, 2005).

In 2003, a business based networking site known as LinkedIn debuted. It became possible to make voice calls over the internet using a software application known as Skype. MySpace and Facebook appeared within a year of each other as social networking sites. YouTube made video sharing possible in 2005, and Google Earth offered a global satellite mapping program to subscribers. A social networking and micro blogging site called Twitter launched in 2006. In 2009, Google Docs provided free web based services such as word processing, spreadsheets and data storage.

### **Organizational Development and Social Capital**

Businesses were quick to notice the potential for the internet to transform organizations, and numerous case studies examined this theme (Galliers & Baets, 1998; Wenger, 1999; Khosrow-Pour, 2008 ). One study (Dimaggio et al., 2001) isolated three policy issues effecting the social impact of the internet: equality of access; enforceable norms for privacy protection; and rules for safeguarding intellectual property. A decade later these issues are still being resolved. By making information move more efficiently among communities, some researchers concluded that the internet facilitates the creation of social capital (Lin, 2001; Wellman, 2001). Longitudinal studies by Kraut et al., (2001) associated internet use with increased communication, social involvement, and well-being. Shah et al. (2001) found positive enhancement of social capital by informational users, but not by social-recreational users. Boas et al. (2006) found that people often turned to the internet as an information source for major life decisions, and that social ties were strengthened when their social networks were then mobilized.

### **Virtual Communities**

Howard Rheingold, a lecturer at Stanford University, is credited with coining the term “virtual community” (Rheingold, 1991). It refers to a group whose members communicate electronically, rather than face-to-face.

In the 1990s, bulletin boards and chat rooms were primary venues for such communications. By 2011, users are more likely to use email based listservs, social networking sites, voice over internet protocol (e.g., Skype), blogs, or texting to reach their cohorts (Meier, 2010). Membership lifecycles for such communities have been studied (Kim, 2000; Lave & Wenger, 1991). Roles adopted by members, as well as degrees of participation, have also been researched (Michinov et al., 2004; Pfeil et al., 2011). Use of the internet for medical and mental health treatment grew so quickly that in 2004, there formed the International Society for Research on Internet Interventions (Ritterband et al., 2006).

### ***THE SELF ISOLATING NATURE OF SOCIAL PHOBIAS***

Social phobias are a subset of the family of anxiety disorders (American Psychiatric Association, 2000). Paruresis, or Shy Bladder Syndrome, is a social phobia estimated to affect seven percent of the U.S. and Canada (Soifer et al., 2001). People with paruresis, known as paruretics, experience intense anxiety when exposed to, or anticipating exposure to, the need to urinate in the vicinity of others. This daily and necessary bodily function is then suppressed until total privacy can be obtained. The phobia encompasses use of public or home restrooms. Heightened feelings of shame may overwhelm a person with paruresis, and the fact of the disorder is often kept secret from family and even spouses. Paruresis is associated with impairments in multiple functional domains, including education, employment, and social relationships. However, neither the medical nor mental health professions evidence widespread awareness of the prevalence or impairments of paruresis (Soifer et al., 2001). As of 2011, only one group has emerged to advocate on behalf of this largely hidden population: the International Paruresis Association (IPA).

### **Origins of the Study**

In 2001, the IPA first attempted to archive its early documents with a goal of someday writing a history. That archive proved invaluable for this study because it had already located and preserved early documents which otherwise would have been lost. Then, as now, one question recurred: to what extent did the IPA owe its existence and continued functioning to the internet? Still, the present account is really just one of two stages in the process of moving from data to facts. It has gathered and put together surviving fragments of the primary and secondary sources, and it descriptively relates those fragments to each other. But it is still unable to interpret them methodically because such a task belongs to historians of a different time and place (Lonergan, 1958; 1976).

### ***HISTORICAL OVERVIEW OF THE IPA***

In April 1996, Steve Soifer, an associate professor of social work in Baltimore, disclosed his personal struggle with paruresis to his friend Carl Robbins, a clinical psychologist and non-paruretic. From that conversation there emerged the idea to form a group to support and advocate for paruretics.

A list of "ideas" notes:

- 1) Create National Paruresis Association [NPA];
- 2) Get on [media] talk shows; 3) Write articles...for popular...and professional audience [and write a] brochure; 4) Set up 1-800 number for Association;
- 5) Do group(s) together as co-therapists; 6) Set up support groups; 7) Write NIMH grant?; 8) Network with other anxiety...programs and hospital urology...associations; 9) Presentation [at] next year's ADAA meeting? (Soifer, 1996a).

Later notes mention a book as one possible action, and suggest that "support groups would allow [the] reclaim[ing] as [a] group [of] public restrooms", to be designed to provide greater privacy for both genders (Soifer, 1996b).

Within a few months, a board began to form. The Americans with Disabilities Act (ADA) was considered as a means to force policy changes in restroom design. No documentation from that time has been found which refer to using computers or the fledgling world wide web to identify paruretics or disseminate research findings.

However, the usenet provider America On Line, around 1995, had carried a newsgroup titled, as best can be recalled, "alt.support.can'tpee.in-public". Started by a young man known only as "Ryan", it was an open and unmoderated discussion. Unfortunately, the newsgroup format did not work well for sensitive material. Another man, "Richard Z", had run a mail list for vetted individuals and he later received the go-ahead from his internet service provider to put up a website on paruresis: <http://www2.cy-net/~richardz/ajw47598.html>

That website became known to NPA and its high level of activity was an impetus for making the NPA a "membership organization" (Soifer, 1997). In May 1997, Soifer and Robbins held a workshop attended by eight paruretics; it was advertised solely on the website message board. Board meetings were conducted by mail (both e-mail and U.S. Post) until 1998. A first draft of the annual report was lost to computer (or operator) error: a frequent frustration for PC users of that time. A memo also records the first chastisement of board members who had not yet paid dues. Media interviews via print, radio and television were an emphasis of the early years as the IPA sought to identify itself to paruretics, reduce their isolation, and normalize discussion of paruresis among the medical, psychological and general populations. These goals were given weight in 1997 with release of the Harvard Medical School Study, a sub-study of the National Co-Morbidity Study. Its findings indicated that about seven percent of the U.S. and Canada has difficulty using bathrooms away from home ( Kessler, Stein & Berglund, 1997).

December 1999 saw the merging of "Richard Z 's bulletin board with the IPA website. A member known as Craig I. devoted considerable time to enabling "paruresis" and variant keywords (e.g., shy bladder; pee shy) to appear in a variety of search engines . This action alone greatly enhanced any individual's ability to find and connect with credible information about their symptoms. By early 2000, the new website had already recorded 20,000 hits, and its message board counted between fifty and a hundred active users. The recording of website viewers, known as hits, was a common tool of that time for assessing interest and tailoring website content. The website now had a link for "Official IPA Announcements" (such as a list of scheduled workshops, and a copy of the financial report). Also by this time, Joe Himle and Soifer had worked out "a very effective treatment protocol" (Soifer, 2000) for paruresis, using graduated exposure therapy. Indeed, cognitive behavioral techniques were found so effective that questions of etiology (that is, what caused the paruresis) were deemed largely tangential.

With commercial availability of enhanced encryption and the debut of PayPal, the website was able to safely transact credit card payments. This augmented the IPA's fund raising through sale of publications, workshop registrations and donations. Although grant writing was pursued, only one organization so far has awarded IPA a grant. The evolving interests of IPA are summarized in its committee structures: ADA/Drug testing; Legal; Education/outreach; Finances/fund raising; Public relations; Research; Medications, NIMH; Literature; and Medtronics Interstim. In 2002, the website recorded one million hits. IPA was in contact with the director of the Selective Mutism Society, who reported that half the children they saw also had avoidant paruresis (Soifer, 2002). Within four months of moving into its first office, IPA had outgrown its computer operating system, its mode of internet access, and its printer. The e-mail distribution list numbered about 1,000. There were three international websites -- for Toronto, South Africa, and Europe -- with the U.K. site the oldest. IPA's Board of Directors acknowledged its U.S. website as "the lynchpin of the organization" (Soifer, 2002).

By the ten year retrospective in 2007, IPA had fostered two interrelated organizations: the American Restroom Association (ARA) and the Shy Bladder Institute (SBI). The main IPA website was redesigned, and averaged 800 unique hits each day; the SBI website averaged 200 hits; and the ARA site averaged more than 1,000. Although perhaps not a household name, paruresis had become a term more familiar to the media, to the general public using search engines, and to the medical and psychological communities. The Oxford English Dictionary has accepted paruresis as an entry in its online edition. Meanwhile, more and more people have become familiar with the more generic term "shy bladder."

As of 2011, the IPA continues to host treatment workshops around the world, and to advance understanding of the disorder through presentations and publications in the fields of urology, psychology, social work and workplace drug testing. Support groups exist in 15 countries. Websites operate in 10 countries, with two chat boards in China. The organization is utilizing the new technology of social media by having a presence on LinkedIn, Twitter, Facebook, and YouTube.

As new technologies arise, IPA members continue to evaluate them for possible enhancement of organizational functioning. For example, just as email replaced the US Postal Service for board communications, so too is the latest Voice Over Internet Protocol (such as Skype) displacing in-person attendance at annual meetings. Google Documents is being used to enable geographically distant researchers to collaborate on professional publications. In 2011, an IPA sponsored video on paruresis was posted on YouTube (available at: <http://www.youtube.com/watch?v=hOOK8aial5w> ). The US IPA website is linked to Facebook, Twitter and Linked In (available at: <http://www.paruresis.org/> ).

Finally, IPA members, workshop attendees, and survey subjects report common experiences in their movement from isolated, misunderstood suffering to a sense of informed understanding and community. Initially, individual paruretics felt socially isolated by their symptoms: within their families, at the workplace, and when seeking health or mental health treatment. By using internet search engines and particularly the IPA website, they could become better educated about the condition and its prevalence, and take this information to their communities and healthcare providers. Moreover, they could meet other paruretics through email correspondence with a support group leader, or participation in a support group, or attendance at a workshop. Freedom from the self-isolating nature of their phobia could thereby begin.

### **DISCUSSION**

It may be asked whether the internet effected the formation of social capital in a largely virtual community like the IPA. A response will begin by distinguishing the aspects of social capital most relevant here: 1) bonding, and 2) bridging. The first form is found most often in kinship situations: family or family-like ties that hold people together through good times and bad, happiness and adversity. The second form more closely resembles that found in friendships and in workplace settings: voluntary or imposed kinds of relationships in which people from different backgrounds (social, economic, political) can associate and form ties that move through and past their different spectrums. It would be expected that very few changes in bonding capital would occur in a community like the IPA. The general rule is that familial relationships do not form through virtual communities (with the exclusion of dating websites). Although membership surveys show that some friendships of enduring quality have formed in the IPA, their number is small.

With regard to bridging capital, though, it appears that there has been marked growth in this form of social capital during the 15 years since the IPA was founded. We would include here: the hundreds of attendees at IPA workshops over the years and the bonding that occurs in them; the support groups that have formed world wide; the 1500 members of the organization; and member's active online participation in subject threads of the interactive bulletin board. We note that the IPA website receives 350,000 unique hits each year; clearly, it has become a service for many people from diverse backgrounds. Moreover, the subject threads of the online bulletin board allows users to share their experience or ask questions -- and this is done in a generally supportive environment.

There are two areas in which the internet has played a crucial role in the continued growth of the IPA. First, there is the role of anonymity. The organization's website is devised so that anyone can access most of its information and resources without revealing his or her identity. Thus, unless one registers for the interactive bulletin board or becomes a member of the organization, no one can be identified as having perused the website.

Second, with the improvement of search engines over the years, merely entering any word or phrase related to "shy bladder" will find the IPA. Membership surveys indicate that approximately 4 out of 5 people first learn about the organization in this way.

### **CONCLUSION**

The present case study supports some of the findings of Jones & Meier (2011) and of Meier (2010). In the present instance, IPA's capacity to adapt to evolving internet technology meant that it has not only endured for 15 years, but that the virtual community it reaches continues to accommodate new members. For example, IPA designed a YouTube video to reach a generally young demographic. Its willingness to move to VOIP for board meetings is a recognition of the increasing time constraints of modern life. Ongoing development of its website -- from a simple message board in the early years to its present international user forums -- both keeps IPA relevant and enables it to attract a broader audience.

Second, IPA appears to have positively fostered bridging capital: virtually through the very high number of unique user visits, and in-person through the worldwide support group network it has launched. One of IPA's initial goals was to "set up support groups" (Soifer, 1996a) ; this goal developed into leaving a support group in every place a workshop was offered. Thus, as Jones and Meier found (p.116), "the empowering of members to become leaders and organizers" has functioned as both process and result.

In the case of IPA, individual paruretics first obtain credible information about their symptoms from the website. They then may choose whether to read a publication or, further, to attend a workshop (such attendance marking a definitive moment in the movement away from social isolation). Some workshop attendees have then felt empowered to participate in, or even found, a support group in their locale.

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