

Fostering social resilience through online communities

An evaluation of the Livewire chat room

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Starlight
children's foundation

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Young and Well Cooperative Research Centre

The Young and Well Cooperative Research Centre is an Australian-based, international research centre that unites young people with researchers, practitioners, innovators and policy-makers from over 75 partner organisations. Together, we explore the role of technology in young people's lives, and how it can be used to improve the mental health and wellbeing of young people aged 12 to 25. The Young and Well CRC is established under the Australian Government's Cooperative Research Centres Program.

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1 Main Messages

Concerns that the overuse of digital technology might prevent young people's meaningful social engagement have received much airtime in the popular domain. The key concern is that time spent in front of a computer, phone, tablet, gaming console or other digital device takes away from time spent engaging in 'real' social interaction. This research documented and analysed how a group of vulnerable young people who regularly access an online community – livewire.org.au – understand their engagement with digital technology and its relation to their offline social engagement. Livewire.org.au auspices, among other things, a moderated online chat forum for young people aged 10-21 who are living with a chronic illness or disability.

The research participants clearly articulated their appreciation for the Livewire chat room as a community of young people with shared interests and concerns. Moreover, they are keen to work together with adults—in this case the Livewire chat room hosts—to construct an online environment that maximises their capacity to negotiate the social resources they need to actively participate in both online and offline communities. The young people play an active role in making the chat room a community in which people feel safe and respected. For the most part, they moderate their behaviour in deference to the range of ages of people using the space and the challenges participants might be experiencing. The participants speak of the chat room as an opportunity to be more fully themselves. Beyond the chat room, digital technology also offers them the space to explore and get feedback on creative work they produce. For some this is a highly valued aspect of what digital technology affords them.

These young people tend to perceive digital worlds as an intersection of online and offline spaces beyond the Livewire community. Friendships formed offline are pursued online, homework is discussed, shopping done, plans made and other services such as online tutoring accessed. The online space provides opportunities not available offline. For some participants this is because their illness or disability prevents them from fully participating in the offline communities of their peers. For others online spaces allow their creative work to reach a broader audience. Further, several young people in the study described the affordances of digital technology in terms that pointed to their assistive nature, highlighting, for example, text-to-speech apps and scrolling subtitles on movies.

This study found that digital technology can positively disrupt the usual life of young people living with a disability or chronic illness. Technology provides the conditions for creating an 'interrupted space' (Bolzan and Gale, 2012) for these young people in which the physical limitations of their condition, the expectations of others and feelings of isolation no longer completely define the parameters of their world. This new space fosters social resilience; they are able to support each other and contribute to broader understandings of the illnesses or conditions with which they are living. Online spaces allow the young people to create a community that is supportive and respectful, a place where they can offer and receive authentic understanding and appreciation of the difficulties they and others are experiencing. This space provides access to resources and people otherwise not available to them, and enables them to share about and discuss a variety of subjects and areas of interest. Those resources and contacts young people access online may be at an international or local level, and the ability to negotiate offline experiences and activities online can, in some instances, enable these young people to have a greater awareness of and to become part of their local communities. For these young people, then, the online experience complements rather than replaces offline experiences.

2 Background

The internet is revolutionising human capability, personhood and identity; it is transforming cultures, communities, politics, ethics and social opportunities in significant ways (Kirmayer, Raikhel & Rahimi 2013). Digital technology use is an accepted and generally assumed facet of young people's lives. However, within popular discourse, it is generally cast in terms of concern and distrust and it is often feared as growing out of control. In the last decade, an extensive body of literature has accrued, which examines the relationship between wellbeing and digital technologies, or Information Communication Technologies (ICTs). Numerous articles document the risks associated with technology use. In her review of this literature, Helen McGrath (2009) identified two dominant discourses: the first is concerned with fears of online bullying and/or exploitation; the second concerns the potential for engagement in online worlds to promote social disengagement and addiction (Kuss & Griffiths 2011; Young 2009; Young & Rogers 1998). These fears are regularly picked up by the mainstream media; for example, *The Telegraph* headline: "Student 'addiction' to technology 'similar to drug cravings', study finds" (Hough 2011).¹

This concern that online worlds are dangerous places is exacerbated when it is directly connected with young people's use of online technologies, and intensifies when addressing the practices of vulnerable young people. Löfgreen-Mårtensen (2008) found that family members and people who work with young people with a disability often see them as lacking sufficient skills to be able to navigate computers and the internet safely. Blanchard, Metcalf and Burns (2007) found that such concerns often result in parents limiting the time spent on computers and the content viewed.

Underlying many of the mainstream concerns about young people and technology use are assumptions that young people are in some way passive or powerless occupants of online worlds; that they are the potential victims of or ensnared by the technology with which they engage. That is, these fears are regularly underpinned by a discourse that constructs young people as ill-equipped to negotiate complex environments, or that positions young people as "becoming" (Qvortrup 1994), not yet able to make adult-like decisions and requiring protection.

Vulnerable young people frequently use ICTs to access information and help for their mental health and wellbeing. ICTs encourage interactive participation between young people and those who work with them as well as enable professional interactions (Burns & Birrell 2014, Burns et al. 2010). Technology is increasingly used in mental healthcare, consumer advocacy and support groups, as well as for the delivery of health information, web-based consultation, treatment intervention and mental health promotion, and can be particularly significant for those isolated by stigma or distance, for example those in rural and remote communities (Kirmayer, Raikhel & Rahimi 2013) or in otherwise challenging contexts (Zinck et al. 2013). Although a detailed review of specific interventions with young people using ICT (see for example Barak et al. 2008, Merry et al. 2012, Whittaker et al. 2012, Mathers et al. 2009) is beyond the scope of this study, a 'digital disconnect' between young people and their health workforce still needs to be understood and bridged (Blanchard et al. 2011).

Subsets of studies have specifically considered e-interventions for those belonging to minority groups and/or young people with chronic illness or disability. ICTs may offer sexual

¹ The article bases its argument on the research project Unplugged, which collected and analysed the responses of more than 1000 university students who went offline for 24 hours (Moeller, Powers & Roberts 2012).

minority youth and young adults significantly safer spaces and vital community support as well as knowledge, education and sometimes professional care, which contrasts with their frequent experiences of exclusion and victimisation offline (Craig et al. 2014). Other social networking sites have for example worked with young people with Type I Diabetes (Sprod, Agostinho & Harper 2014; Gerber et al. 2007) and adolescents and young adults with hearing loss (Middaugh 2013). Findings suggest that tailored one-to-one support at home and training for families to learn to use the internet for building social networks may facilitate online social participation for youth with a disability; though the intensive nature of some investigated programs may limit their expansion (Raghavendran et al. 2013).

Still fewer programs consider group ICT interventions with young people with chronic illness or a disability (see Maurice-Stam et al. 2014) or analyse the impacts of moderated/hosted arrangements. One study describes how online participation via a moderated chat room setting promotes the social inclusion of young people aged 15 to 25 years who are living with a disability and who were either geographically or socially isolated (Burns & Blanchard 2009), and enables them to successfully negotiate stigma, isolation and mental health challenges. This is especially so for young people living in rural areas who have limited access to communities of support.

What is frequently missing from this discourse is the voice of young people explaining how they understand and negotiate their technology use. What sense do they make of the technologies they use, and to what extent are they active in their engagement with them? What does technology offer and afford them, and how does it sit in relation to their offline worlds?

This study was thus undertaken with a group of vulnerable young people known to regularly use digital technology—all members of Livewire, living with a chronic illness or disability—with the aim of identifying how they use and make sense of digital technologies in their lives.

Social resilience has elsewhere been defined as comprising of agency, non-totalising identities, valuing of contribution, a responsive community, public space, respect, and hope (Gale & Bolzan 2013). In the context of this research these are understood as:

- Agency—being authors of their own solutions, rather than adults or those in positions of power or authority directing or deciding what is best for them.
- Non-totalising identities—the importance of not assuming people can be fully categorized and defined by a fixed set of assumptions.
- Valuing of contribution—what the young people are doing is real, it is not a rehearsal for some future in which they will be able to legitimately or ‘actually’ contribute.
- A responsive community—the importance of others connecting with and responding to their contribution.
- Public space—the necessity for action to take place in a public space.
- Respect and trust—the fundamental human need to be respected and to trust must be met if social resilience is to be invoked and sustained. What they identified was the bi-directional nature of this respect, “you respect them and they’ll respect you” emerged as a clear understanding of how relations need to be in a socially resilient community.
- Hope—“that fundamental disposition to work towards a better future based on a realistic appraisal of current conditions” (Shade 2006, p. 212).

Using an innovative approach, this study gives a voice to young people and explores how they negotiate their offline and online worlds, and the interactions between the two, and how technology can also contribute to increased social resilience.

3 Livewire

Livewire.org.au – connect, support empower

Livewire.org.au (Livewire) is an online community connecting young people aged 10 to 21 years living with a serious illness, chronic condition or disability, and their siblings, to help increase their social inclusion and enhance their sense of connection and community. Livewire aims to lift spirits, enhance self-esteem and build resilience.

Livewire facilitates connection, empathy and understanding between people who are experiencing similar situations by offering a customised, safe and secure online community in which members can connect using social networking tools and can engage through sharing digital content. The features of the Livewire platform include:

- Online chat
- Blogging
- Member profiles
- Games
- Music
- Articles
- Community groups
- Competitions

Livewire hosts provide live chat sessions for two age groups: for members aged 10 to 15 years and for those aged 16 to 21. Members undergo a strict sign-up and identity checking procedure before they are able to join the community. Further, members under the age of 18 can only join under the condition that they do not disclose any identifying personal information without the consent of a parent. These measures mean that Livewire members are guaranteed a high level of safety.

Member interactions and content are moderated by professional chat hosts trained in adolescent health and wellbeing. All chat hosts are employed on casual contracts and work part-time in their role. The presence of and ongoing moderation by chat hosts in the Livewire community differentiate the platform from other social networking services for young people such as Facebook.

In addition, the Livewire community enables other organisations to set up their own Livewire page, offering a safe platform for organisations to connect with young people that utilise their services, and providing them with event updates, resource information and support relevant to their condition. Examples include Asthma Australia, Disability Sport and Recreation, and Epilepsy Action.

4 Methodology

There are two key components to this project: the first concerns the place of digital technologies in the online and offline lives of the young people, the second concerns the ways the young people use the Livewire site.

In October 2012, Livewire hosted an online chat session in which researchers from Western Sydney University talked with 13 members of the Livewire community, with the objective of understanding how the young people engage with and experience digital technology use, and how their digital practices relate to their offline social engagement.

Participants were recruited via a call posted to the Livewire community inviting all members over the age of 16 to participate in the research project by logging into Livewire and joining the one hour discussion in the main chat room. Livewire members who did not want to participate were able to join other chat rooms for the duration of the research chat. In accordance with Livewire policy, a Livewire chat host was also present as a silent participant.

The Livewire team members and researchers from Western Sydney University co-developed a set of questions that formed the basis of the data collection. These questions (See Appendix 1) were designed to explore:

- The extent and purpose of participants' technology use
- Participants' membership of offline communities
- The cross-over between participants' online and offline activities and networks
- The relationship between participants' engagements in their local area and their online activity
- The impact of participants' online activity on their offline activity
- How participants develop and use creative content

The data collected was subjected to a thematic analysis using an interpretive reading of the data (Mason 2002) to gain insights into how young people living with a chronic illness or disability understood their experiences of engaging in the Livewire chat room.

In August 2013, following a similar process, Livewire posted an invitation to all its members over the age of 16 to participate in a follow up online chat session.

Following on from the second chat session, further analysis (Hsieh & Shannon 2005) was undertaken with the aim of identifying the main responses by the participants to each of the questions, drawing on key words and ideas expressed by the participants. Participant responses to the questions posed in the Livewire chat were grouped into discrete responses (Klemm 1986), with agreements, repetitions, and disagreements recorded in order to provide some basic frequency figures. This then formed the basis for the following discussion of findings. Statements highlighted in bold throughout the Findings section of this report are quotations from participants.

Ethics approval for this project was granted by the Western Sydney University Human Research Ethics Committee (No H9507).

5 Discussion of Findings

While this project focuses on the Livewire chat room, the participants did not limit their discussion of their online practices to this one platform; rather, they articulated what is distinct about the Livewire chat room whilst also reflecting on aspects of their experience using other sites and platforms. The research revealed a series of findings around four key themes: community, digital literacy, the interactions between young people's online and offline worlds, and constructions of identity. Taken together these findings help further the understanding of and aid in developing better approaches to building social resilience online and offline.

5.1 COMMUNITY

In general, adults are often concerned about young people's online engagements; they tend to make assumptions regarding young people's conduct online and regularly attempt to control young people's movements online. By contrast, Livewire provides a different type of relationship between young people and adults where they work together, share leadership and sustain a culture of respect. At the same time, a safe environment is constructed in which young people's needs are met and their manifold engagements are supported. Young people feel affirmed by this relationship.

The significance for young people of being connected, in the sense of feeling part of a network and having trustful relationships with others, is widely acknowledged. In a comprehensive report on youth development theory and practice, compiled by the National Research Council Youth Development Committee, connectedness, or being recognised and valued within a social network, was an identified feature of settings linked to healthy adolescent development (Eccles & Gootman 2002). Even beyond the community of Livewire, the participants spoke of the value of receiving feedback from the wider online community on their contributions. A clear purpose for young people's engagement with Livewire was that of co-creating a community. What 'community' means to them was the focus of several questions and discussed at length in the research chat session. Participants noted that community:

Feels like you were always meant to be there;

Feels like its home;

Place where you feel like its home, a place where you are bound by similar interests or location;

Similar values, interests or aims, collaborate to support each other and achieve things that one alone could not achieve, such as Livewire;

A group of people who support each other, are there for each other, have something in common be it geographic location or something else;

Each person belonging, empathy and leadership but not over controlling.

Acceptance, respect and trust, friendship and acceptance, honesty and trust, acceptance, tolerance and open mindedness;

Understanding, empathy, willingness to cooperate and accept views that may differ from yours.

Participants' understandings of 'community' are closely related to ideas of home and sharing a space with people who have something in common and who trust each other. The idea of belonging is most significant— young people with chronic illness or disability may be aware of all types and forms of communities; yet, they may struggle to identify commonalities with other group members and thus fail to develop a strong sense of belonging. While one participant stated online and offline communities generally serve the same purposes, some Livewire members articulated distinctions between online and offline communities. One participant, for example, outlined the obvious difference in removing the physical interaction in an online setting.

I can't give someone a hug or a hi 5, and it poses difficulties for those who rely on hearing for communication not sight.

A common observation, however, was concerned with having the power to choose where you belong:

Online communities are different in that they are more accessible, you have greater freedom to choose which ones you become part of.

This interest in having a choice illustrates the significance of agency for these young people. It shows they consider their options and actively seek engagement. Such statements illustrate that online communities are intentional communities—communities of adoption— rather than accidental communities people join by circumstance. This offers the participants greater autonomy. An even more noteworthy difference between on- and offline communities was identified by the chat room members: the removal of certain barriers which are often perceived to impede their engagement with offline communities:

It removes the language barrier because it's all text.

I'm more confident online... I have speech impairments and I can get my ideas and opinions out more easily online.

In real life I'm more likely to tell some-one to take a long walk off a short pier.

It's better online because we can chat about personal stuff that might not be able to be discussed face to face.

It [online] gives us freedom to speak our minds, I feel when I'm out in the open I can't speak my mind as I have judging eyes on me.

The partial anonymity of online spaces paradoxically enhances disclosure, facilitating engagement. Here the lack of some characteristics of 'traditional' (offline) social exchanges seems to create new opportunities. Engaging online seems to overcome ordinary inhibitory social processes and personal self-judgments; it bypasses internal and social censorship, while supporting freedom of thought and courage in expression. In a world of increasingly

steep gradients between poor and rich, and those who live with and without disabilities, digital technology acts as a leveller, allowing these young people to harvest opportunities that might otherwise not be available. It is also possible, though information about this was suggestive rather than definitive, that young people with disabilities or chronic illness use the opportunity to make their audiences more aware about their lives—highlighting gaps between values and practices as well as disclosing justice claims and providing platforms for their redress (Schaffer & Smith 2004). In all these ways, digital technology helped to reduce challenges associated with disability. In the chat room, participants' physical limitations matter less for an engagement with other members. This allows the young people to be themselves, without having to constantly negotiate, explain or discuss their impediments. In a way this removes an entire layer or aspect of their identity, enabling them to be more confident in expressing themselves. Many participants agree that online communities permit more open communications, but others expressed the general view that online and offline communities were comparable in some respects in their rules of etiquette.

I think it's like any community you're in, you think about what you say before you say it, like there is a time and place for everything.

This dominant stance illustrates that the Livewire environment does not present a *carte blanche* for unfettered freedom of speech. If anything, it holds participants to a higher standard of communication than offline environments.

The participants are authentically engaged with each other and make genuine and important connections. Participation and contributions to the online chats are real and in knowing this the young people take personal responsibility for maintaining certain standards of behaviour online. There is no sense in which this activity is a rehearsal for 'real' participation in offline communities. Rather, their online engagements are viewed as just another dimension of everyday life, just as 'real' as their offline participation.

The respect and safety of young people on the Livewire site is clearly of great importance to members. Previous research highlights the importance to young people of believing their actions will be meaningful and have an impact (Boeck, Fleming & Kemshall 2008, p.7). The behaviour and the tone that members have adopted on Livewire is clearly in acknowledgement of the diversity of other members and the responsibility the participants have for caring for others on the site. They believe that all people accessing Livewire need to feel safe on the site and free to discuss issues of concern to them. Also, they need to feel free to let it be known when they are struggling or having a difficult time. The participants are fully aware that the language and contents discussed need to be suitable to a wide range of ages and life stages; and they take responsibility for ensuring this happens.

Even though rules have been made by adults and are a condition of participation on the site, the young people engage with these rules and articulate a caring justification for them. Previous research demonstrates the importance of rules being negotiated with young people in a way that creates a set that is meaningful to young people as well as the adults (Bolzan & Gale 2010).

The self-moderation is something we need to have in order to have younger members as part of the community and we value people of all ages so it's something I'm happy to do to be able to have them here.

I don't use bad language on here, not that I use it that much anyway but I make an extra effort, I'm more moderated.

I'm a bit kinder on Livewire.

In real life I regularly make dirty jokes, hold 'adult specific' conversations regarding alcohol, drug use, sexuality [etc.], whereas in Livewire I'm more mindful of how I need to be.

...and more sensitive to the different ages and cognition levels within the community.

I'm also more tolerant on here.

Several people made this last comment in relation to their participation on the Livewire site in particular. The young people noted that rules, norms and ways of behaving are essential to a good, safe online community. A very clear theme emerged of young people taking personal responsibility for the way they participated online. The conversation involved several comments that articulated the rules for the Livewire site:

There's a ban on certain language.

Definitely in the sense of adult content and language...and political incorrectness. (Many participants supported this comment)

There are filters that block certain words and you can get in trouble for using certain language.

A logic emerged of why these rules existed:

It's a safe environment to reveal how we're going, and talk about anything, pretty much, and we're all careful to make sure it stays that way by being considerate of what we say and making sure to be supportive and caring.

Well, I guess you have to be more understanding of people on this site and in terms of the moderation we have a set of rules we have to follow and we all follow them, you get a certain amount of good intention where you won't find on places like Facebook.

There are certain rules on Livewire we have to abide by, and I'm sure we all don't mind that.

One noteworthy finding was the value placed on the participation of adults in the Livewire chat room, who not only moderate the discussion but are also a part of the community. The co-created world that emerges in the Livewire chat room is a testament to the skill and professionalism of the chat hosts, who provide information, thoughtful leadership, organisational structure and participatory encouragement as well as social and emotional support. Where necessary they also successfully manage challenging (mental) health situations. A key component of their roles is performative; creating, projecting and maintaining a persona that engages with their target audience (Third, Kelly-Dalgety & Spry 2013). The adults were seen as integral to the community; they were not seen as controlling but were clearly described as caring and invaluable members of the chat room:

We hold the chat hosts in very high regard. We all get a bit upset when we lose one we're close to.

We enjoy our time with them because we really do enjoy being with them so much.

We respect the workers here so much and as a result we respect the rules set by them.

[It's] more moderated but then again because [it's] moderated [it's] more safe and we won't get hurt or cut down if we express ourselves or make ourselves vulnerable, unlike other sites.

The respect shown on the site whilst very clearly relating to the need to feel safe is also about creating a respectful community which includes the adult chat room hosts. It is apparent that there is trust on the Livewire site. Previous research (Bolzan & Gale 2012) finds tension between 'care' and 'control'. It is apparent that young people may experience interventions or rules—although well intentioned—as controlling, thus inhibiting their participation. It is interesting to note that the development of rules is not seen as problematic or controlling in this context, as has been previously identified (Third & Richardson 2010). On the Livewire site the rules and regulations established are understood by the young people as relevant for safety and respect and are perceived as 'care'. An analysis of the data shows that in being cared for the young people feel safe to take risks and authentically express issues and even discuss problems—qualities that characterise a socially resilient community.

The community created on the Livewire site is described by the participants as qualitatively different from other sites they visit. Livewire is enabling, it allows for honesty and creates a trusting environment in which to authentically participate; it "feels like home". Livewire is a responsive community, everyone is welcome and all comments are treated as valid. Consequently, the Livewire community is seen as an example of a safe place to be: "[Livewire] is safety and Facebook is unsafe". The young people spoke for the most part about how they took responsibility for creating this safe space. They spoke about not criticising those who might be complaining or acting in a gruff manner:

I make a bit more of effort to be understanding and supportive on here, because we all have our battles we're going through and often people have perfectly good excuses to be cranky or something.

The contribution young people made could be seen to reflect evolving aspects of good citizenship evident in the practice of those born in the last several decades and includes virtues of open mindedness, a commitment to mentoring young leaders and responding to community needs (Sanford 2007, p.185). While research suggests that participants in online forums tend to contribute shorter comments, often merely agreeing with other participants (Schneider, Kerwin, Frechtling & Vivari 2002), the discussion in the Livewire community tends to be more engaged. Much of the discussion involved all of the participants reflecting on, endorsing or disagreeing with other participants, but generally in a polite manner. The constructiveness of the discussion can be attributed to the strong sense of connection and community between the young people (Gale & Bolzan 2013).

I love being involved in research projects and opinion polls and surveys [because] they usually are there to improve things😊.

Livewire members demonstrated a strong degree of social capital. Eva Cox (2003) defines this as “the processes between people which establish networks, norms, social trust and facilitate co-ordination and co-operation for mutual benefit. These processes are also known as social fabric or glue”. Two dimensions of social capital that are often discussed are bonding and bridging capital (Putnam 2000). It is apparent through the relationships these young people are developing with each other that their bonding social capital (bonds of connectedness that are formed within homogenous groups) is increasing, but to a more limited extent their bridging social capital (bonds developed across diverse social groups) is also enhanced. The significance of bridging capital is generally seen in terms of improving life chances and improving the capability of overcoming the multiple disadvantage experienced around income, health, education, social problems and housing (Alston 2002). The social capital of these young people can be seen to have increased where they acknowledge the capacity of social media to allow contact with ‘friends of friends’ as well as with people who would otherwise be outside of their networks.

5.2 DIGITAL LITERACY

The participants in this study demonstrate digital literacy and competence, which positions them to better leverage resources and advantages.

Such online skills may provide a conduit to online and offline education and employment opportunities. As Furlong (2011) notes, a person with digital literacy skills can better access education and employment, impacting on inequality, providing economic benefits and enhancing life chances. The young people are exploring new frontiers and collaboration across ages and positions, enabling them to increase their life options and negotiate new terrain.

The digital literacy of these young people is high and they list a variety of applications, platforms and software they use: Twitter, Facebook, Instagram, email, Gmail, Tumblr, videogames, iPhoto, Paint.NET, Sibelius, Audacity, WordPad, WordPress, Movie Maker, ACID Music Studio 7.0, GarageBand, Pinnacle Studio 14, and YouTube. Many Livewire members demonstrate an ease and proficiency with digital technology beyond the knowledge of how to use particular software. Many of the young people are clearly not only consumers of digital technology but also producers of creative work. They blog, write stories, post pictures, make movies and songs.

I also add memes to chronic illness sites sometimes.

I publish stories on external sites as well as my photography.

If you count crafting literary creations as creating, lots of us have blogs or write stories which we share with others.

Post... funny things that come to mind.

One of the benefits of being digitally literate is that many of the young people are able to source, rate and download applications for free. The digitally literate person has a comfort and confidence with digital technology, a willingness to explore and play with it. They are

able to seek out and keep up with developments in areas of interest to them. The availability of free apps is seen to enhance the participants' freedom to explore the digital terrain and also to create content without having to seek permission or financial support from anyone. The comfort with which they use digital technology hints at high levels of digital capital, that is, the intangible knowledge and relationship assets gained through online participation (Chung-Chu 2008). Not only can these young people create and use technology in a variety of ways but, because some applications are free, young people can make their own decisions about what they access and use, rather than requiring adult approval.

Participants report that they use new technologies to help navigate unfamiliar territories. They use technology to help find a tutor when they are in need of one, to determine university timetables, to buy theatre tickets and to obtain information on a variety of matters. This is further discussed in the theme of identity below.

Participants are comfortable with online and offline worlds being connected and intertwined. Their online activity was an adjunct to their offline lives and often enabled them to have greater access and engagement with offline activities. From collaborations on school assignments to finding directions to local youth events, many Livewire members on- and offline activities are interlinked:

I plan catching up with friends online and posting videos and things of what we've done which we often talk about offline.

I plan catch ups, download lectures, email concert tickets but we go to the concert in person.

The internet is great for looking up maps and finding other places on line to purchase things that aren't available around here.

My dance studio has its own Facebook page so I find out news from there.

It's the only way I know stuff, if I didn't know what was going on from my hospital council group I wouldn't know about meetings or anything else.

Participants are also aware of the limitations of technology—being logged out of chat rooms, and internet connections being “soooo slow” are seen as constant irritations to online activity.

Whilst not identifying the technologies as assistive technologies, some of the participants reported using text-to-speech, magnifying facilities and apps that subtitle movies or scrolls live. Being comfortable using these technologies is a significant aspect for developing advanced digital literacy skills, in particular for young people with chronic illness and disabilities. While such competencies are important for all young people, they are even more critical for vulnerable young people, who depend more on gaining access to online communities, as this can be the primary way to engage with their peers. And of course, there are dangers in online spaces, which can be much better recognised, addressed and negotiated by digitally literate and educated participants.

In the Livewire community, young people are not just members but active creators and collaborators who generate and share multiple types of creative content—including blogs, art works, poems, stories and memes—and actively contribute to building and maintaining a strong online community. They also participate in these practices to a greater or lesser

degree on a number of platforms beyond Livewire. They are autonomous and experiment with different types of interaction. This includes both seeking and giving assistance as well as playing in ways not otherwise available to them in their offline worlds.

5.3 EMERGENCE OF A NEW SPACE BETWEEN ONLINE AND OFFLINE WORLDS

The use of the Livewire site to explore how young people living with a chronic illness or disability understand their engagement with digital technology and its relation to their offline social engagements challenges conventional wisdom and highlights divisions between online and offline worlds. The young people in the chat room did not create an either/or distinction between the online and offline worlds. “I look on Facebook for things happening with my group of friends”. This creates a new space conceptually and in practice distinct from either online or offline worlds. This space is a seamless merging and extension of both off- and online worlds. The data shows the young people are clearly deconstructing those distinctions and asserting the interdependency that characterises what may be described as an original, new space; rather than a dualism created by notions of ‘on- and offline’ worlds.

Friendships of emotional significance, for example, occur both online and offline. Many young people are extending their circle of offline friends through the online space rather than replacing real-life with virtual socialising. In particular, young people living with chronic illness or disability, who often have less access to offline communities, get a much greater chance to find people with common interests. It is this initial contact with others that is so much more possible with digital technologies for vulnerable young people, enabling them to expand what are sometimes very limited social networks. Friendship in this new space means that making friends online is considered to be another avenue to finding friends, together with more conventional approaches such as making friends in school or at work:

I’ve met one of my closest friends online and we skype outside the forum where we met.

I talk to my closest friends online, not normally in person but occasionally chat on the phone.

Yes, I’ve just moved so I have no friends so I use the internet to keep up with my old friends.

I find it easier to socialise via text on chat or FB or skype, but I still see people at school and I often only know about social events because of Facebook, so it increases how much I see people face to face.

I use the internet every day but I still try and keep my obligation to see people face to face.

Some of these people seem like family to me I don’t know the majority of people on Livewire in person.

I used to have rules of not adding anyone I didn’t know personally on Facebook, but now I’m an adult I’m happy to add friends of friends, for instance if my friend

had a boyfriend from somewhere I didn't know, so I might add them on Facebook to get to know them better.

The above observations lead to the conclusion that young people in the chat room do not create an either/or distinction between on- and offline worlds. For these young people, artificial debates about what is the 'real' world are out-dated. Any forced polarity between real/offline and unreal/offline worlds is transcended by a seamless flow between on- and offline worlds, in which the online enables rather than replaces connections. The scope of this study meant that it was not possible to investigate the full extent to which bridging capital can provide greater opportunities into networks, services and domains, which may enhance Livewire members' capacity to solve social problems. However the use of public sites such as Twitter, which span multiple communities may imply that bridging capital may be enhanced by digital technology use. This is consistent with Steinfield, Ellison and Lampe's (2008) findings regarding the Facebook usage intensity and bridging social capital. The heterogeneous networks created in that study by students with self-esteem issues constitute great sources of bridging social capital.

Livewire—and digital technology more broadly—provides an 'interrupted space' (Bolzan & Gale 2012) which enhances the benefits of connectivity for young people living with chronic illness or disability. This interrupted space "provides the opportunity for social actors to experience something different, something outside of their usual daily routine, and make meaning of it" (Bolzan & Gale 2012, p.56). Having agency to explore sites and apps unfettered by offline constraints provides an interruption to the young people's usual life worlds and expands the variety of connections possible. The health impacts of social connections and belonging have been extensively supported and documented in the literature (Burns, Blanchard & Metcalf 2009).

A further finding suggests that young people are connecting globally with events, people and activities; they bring this information together for their own use at the local level. The ease with which they explored the world was revealed by comments that discussed shopping globally, searching maps and Google Earth.

I've moved... so I use the internet for the news [because] the newspapers are slow and I can't wait and don't like the 6pm news.

The participants access material goods through online networks. They describe using their technology for shopping as well as accessing educational resources, such as school and university lectures, and other services such as online tutoring when this cannot be accessed through offline sources.

I'm able to go on sites like [Freegal] and an online tutor site because it's paid for by my local library and I can access it because of where I live.

5.4 IDENTITY

Digital technologies provide young people with options for how they represent themselves online. They are free from the constraints created by totalising identities (Dominelli 2002), such as stereotypes of the 'chronically ill' which can lead to limitations and disadvantage. Not only does this technology offer them a tool for engaging in conversations that their health condition may have inhibited, but it also provides the young people with the option to present different aspects of themselves. Valentine and Holloway (2002) express this "as a zone of

freedom, fluidity, and experimentation that is insulated from the mundane external realities of the material world [...], a zone in which it is possible to suspend the 'real' self" (p.304). For some this is a more moderated version of themselves, for others it is a chance to occupy an expert status and contribute their expertise gained from experience. The young people can choose to present various facets of themselves in online sites, but nonetheless maintain integrity of identity:

Even if you try to be different online you are still the same person”.

Within this sample many young people indicate they are choosing an identity that is more moderated and consistent with the values of the community:

I am a moderated version of myself on Livewire. In real life I have a much more adult sense of humour.

Many did however indicate that they can present differently on other sites. The recognition of different norms in the various online communities is an important insight gained in relation to the functioning of communities more generally. It illustrates an increase in the members' awareness towards the consequences of their own actions and the ways they represent themselves.

I moderate myself on other websites, but on other websites that's just an option.

I have an [Instagram] so I guess I create an image of myself on there.

I feel like to act happier on Facebook.

I moderate myself more on Facebook, anything online really [because] that can be reposted anywhere.....I would say I talk about my private stuff on here than [anywhere] else.

I'm more controlled and less open about what I'm REALLY going through and emotions I'm experiencing (on other platforms) because people on for example Facebook would be empathetic but not used to the constant medical terminology and experiences I'm going through.

The last statement also illustrates the creation of a sense of community with shared understandings, which is so particular to Livewire and is not usually achieved on other, more general, social media sites. This sense of creating a shared identity around collective experiences can only develop on a site designed for a specific population. Still, many Livewire members are registered with a number of sites. Participating in various forms of social media enables the young people to explore different aspects of their personality. The young people spoke about how they explore and present different aspects of their personality on different platforms:

I'm pretty loud and outgoing on Livewire, while outside I feel I'm more quiet and reserved.

I'm a bit kinder on Livewire.

I think I'm louder online than I am in person haha like I talk more and say more online than in person.

Many participants understand that they cannot rewrite their entire personality. Beyond the explorations into options of self-representation online, many participants acknowledge the possibility to be more fully themselves:

On here I'm more able to talk freely about what's going on and to express my full emotions and give all the details because people understand and I don't have to pretend to be happy.

I'm able to take part in conversations more readily when online because there's no hearing issues and so I'm able to be more confident and speak out more.

It's just down to I can type faster online and my speech is harder to understand than most people. I have speech impairments so it's more that I can get my words and ideas and opinions out easier online.

In addition to allowing young people a form of control over how they represent themselves, in the online community, young people's identity is also shaped by how they are perceived by other members and, through a two-way process, by what young people make of the feedback they may receive. The importance of being heard and receiving feedback was expressed by several participants who commented that they looked forward to getting feedback:

I like getting great feedback and letters from people about my writing.

Yes I like getting other people's opinions. More so on Livewire and [Youtube] but not so much on Facebook.

I know it sounds superficial but I do like getting likes on my photos as well.

Being able to engage through multiple social networking sites means young people are also able to connect with a much wider community that acknowledges their contribution. The feedback in digital forums on stories, photos and comments is valued and appreciated by the young people.

The concept of construction of identity also became apparent in a broader context of 'having an identity within the group' or, in other words, through their participation within the community. Whilst contributions are made by individuals, the young people clearly articulated a sense of themselves in the context of a dialogue with the greater community. Digital technology enables them to not only explore and construct their own individual identity but also to develop a collective sense of identity through their engagement within that community. The mirror created by the responsive communities with which the young people engage enables a journey of co-discovery fostering a greater awareness of themselves as having agency. The kinds of responsiveness and connections created online are at the very heart of social resilience.

Young people describe agency in both the way they conduct themselves online and in the ways they use the spaces provided by digital technology. Agency can be understood as young people "hav[ing] the possibility and freedom to create, change and influence events"

(Boeck, Fleming & Kemshall 2008, p.6). Through their comfort with the technology, the young people in this study are problem solving, for instance, in relation to online safety, and in negotiating familiar and unfamiliar domains and managing life complexities (Furlong 2011). There was an autonomy expressed by the young people around how they were with digital technology – “I can do anything on it. Anything.”

While research suggests that participants in online forums tend to contribute shorter comments, often merely agreeing with other participants (see Schneider, Kerwin, Frechtling, & Vivari, 2002), the discussions in the Livewire chat room are more balanced and nuanced. Much of the discussion involved all of the participants reflecting on, endorsing or disagreeing with other participants in a respectful manner. The constructiveness of the discussion can be attributed to the strong sense of connection and community between the young people (Gale & Bolzan 2013).

Livewire, and perhaps more-so other sites, clearly function as a public space in which comments can be widely broadcast and re-posted by others. The capacity offered by digital technology to participate in public forums, contribute to public debates and receive acknowledgement from people outside their immediate networks is identified by these young people as significant. Matthews, Limb and Percy-Smith (1998) argue young people are seemingly invisible within the “fourth environment”, those public spaces beyond home, school and playground, and provided only with “token spaces”, often inappropriate to their needs and aspirations and are essentially being marginalised and excluded from adults’ public space. The forums offered by digital technology challenge this invisibility or the relegation of children and young people to “children or young people’s spaces” and afford opportunities to engage in adult worlds. Engagement in public spaces, whilst marked by the spectre of indelible comment, also provides opportunities for the young participants to be heard and to participate in ways not otherwise available to them.

The Livewire online community creates a new space in which they can explore aspects of themselves. For these young people any limitations they daily experience may relate to their current level of disability or illness but it might also be affected by adults’ expectations of them and assumptions of their capacities. The benefits flowing from authentic connection to an online community offer an intriguing way of exploring further health advantages of belonging to this new form of community. The experiences and connections the young people create and are involved in, suggest that their use of the Livewire site—and possibly other digital platforms—enables them to generate communities in which all members have agency and interact in ways which are meaningful and authentic.

6 Conclusion

This study was undertaken in partial response to the expressed concern that digital technology offers a seductive and addictive alternative to ‘real life’. It investigated, together with young people with a chronic illness or disability, the extent and purpose of technology use. Moreover, it explored the cross over between online and offline activities, the relationship between the participants' local area and online activity, the impact of online activity on offline activity, as well as their development and use of creative content. The findings suggest that new forms of resilience may be created where on- and offline worlds intersect and merge.

Members' engagement with, contribution to and thoughtful use of the Livewire chat room suggests that beyond providing a forum for discussion and connection with other young people similarly placed, it can, more holistically, enhance social resilience. The Livewire chat room has increased the young people's agency and given them the opportunity to practice interacting on this site as well as others they might explore. They are able to choose not to self-represent as a young person living with a chronic illness or disability on the sites they use; they could also be a ‘moondoggy’ if they chose. Their participation on Livewire, and other platforms more broadly, is experienced as truly authentic. The young people are very aware of the impact their comments or interactions would have on others. They express a sense of deep responsibility for creating a place where others who may feel vulnerable can feel safe. Their interactions are not a rehearsal for when they ‘grow up’; they are real and happening now. The participants are responsive to each other and indicate that they also find this sense of responsiveness in broader online communities, particularly when speaking about the acknowledgement they receive for their creative content on a variety of sites.

The digital technology used on the Livewire site creates an ‘interrupted space’ in which young people can ‘be’, in a way not constrained by physical health limitations, expectations of others, or isolation. The community they have co-created on Livewire, along with the proficiency in digital technologies they develop there, appear to increase their social resilience; a resilience that happens only in community and through the prospects offered by being authentically engaged with others; and that provides the opportunity to thrive and transform in the face of chronic adversity. It enables increased confidence and autonomy and provides a forum in which they are heard and acknowledged. The Livewire online community is not portrayed by its members as an alternative to the ‘real world’, rather it is fully embedded in these young people's day to day lives and becomes an integral part of their ‘real world’, a new space in which these young people live, interact and play, a space which both merges with and enhances their multi-dimensional lived experiences.

Ghassan Hage (2003) has suggested that society should operate to distribute hope. In this project, young people's narratives indicated that there is a gathering of hope in their use of technology. That is, whilst there is a risk that young people living with disability or a chronic illness may experience a dissipation of hope, on the Livewire platform we see the opposite—most participants were focussed on the space, opportunities and the richness of possibilities provided by digital technologies and their interactions with others via Livewire.

The data from this research revealed that the Livewire community is a co-created space in which young people living with a chronic illness or disability are able to develop social resilience.

Social resilience is strengthened and refined in the Livewire chat room, enhancing young people's participatory capacities and extending their life chances.

Author Biographies

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Delphine Bellerose is a research officer in the Institute for Culture and Society at Western Sydney University. She has a background in social policies management and extensive experience in community research and data analysis. Delphine has been involved in both quantitative and qualitative research projects on various topics including trends in treated alcohol and drug problem use, customers' experiences with telecommunications providers, cybersafety, and children's rights. She provides research support to the Young and Well Cooperative Research Centre's project 'Transforming Institutions and Community Perceptions', which is part of the Connected and Creative Research Program.

Professor Natalie Bolzan

Natalie Bolzan holds the Margaret Whitlam Chair of Social Work at the Western Sydney University. Her major teaching areas are around social policy and ethics. Her principal area of research is concerned with exploring the ways in which marginalised groups such as the young or those with mental illness are able to resist or alter their marginalised status and achieve agency. She is particularly interested in methodologies which seek to engage young people in research which concerns them.

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Frances Gale is senior lecturer in social work at Western Sydney University and a member of the Transformational Practices Research Node. She has extensive experience in research and work with marginalised groups, particularly but not solely with young people including young people from traumatised backgrounds. Her most recent work includes research with indigenous young people and community engagement. She has a particular interest in research around strengthening communities, social resilience human rights and participatory citizenship and writes extensively in these areas.

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James Herbert has recently completed his PhD on 'Practitioner Learning from Evaluation', which explores the challenges around connecting research and evaluation to practice in the high politicised context of human service practice in non-profit organisations. He has also worked as a research officer on an Office of Teaching and Learning project looking at how undergraduate programs at Australian universities embed graduate attributes into their curriculum. James has also previously worked as a senior research and evaluation officer in the Department of Corrective Services (WA).

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Aaron Millerand is a young disability consumer advocate who recently completed his bachelor of Social Work degree with Honours research which focussed on the voices of young people with disability in tertiary education. He also has a particular interest in digital technologies. Aaron worked as research assistant on the project, having input into all aspects of the project, including a major role in analysing data and writing the report.

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Bettina Rösler is a research assistant and teaching instructor at Western Sydney University. She holds a PhD titled "Reimagining Cultural Diplomacy through Cosmopolitan Linkages: Australian Artists-in-Residence in Asia" from the Institute for Culture and Society (Western Sydney University). Bettina has also completed Masters in English Literature/Cultural Studies at TU Dresden (Germany) and in Translation Studies at Auckland University (New Zealand). The primary focus of her work is the translation of cultures and intercultural

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References

- Alston, M 2002, 'Social capital in rural Australia', *Rural Society*, vol. 12, no. 2, pp. 93-104.
- Barak, A, Hen L, Boniel-Nissim, M & Shapira, N 2008, 'A comprehensive review and a meta-analysis of the effectiveness of internet-based psychotherapeutic interventions', *Journal of Technology in Human Services*, vol. 26, no. 2-4, pp. 109-60.
- Blanchard, M, Metcalf, A & Burns, J 2007, 'Marginalised young people's use of information and communication technology', *Bridging the digital divide: creating opportunities for marginalised young people to get connected*, Inspire Foundation, Melbourne.
- Blanchard, M, Herrman, H, Frere, M & Burns, J 2011, 'Attitudes informing the use of technologies by the youth health workforce to improve young people's wellbeing: Understanding the nature of the "digital disconnect"', *National Youth Sector Conference 2011: Interrupting Transmission*, Young and Well CRC, Melbourne.
- Boeck, T, Fleming, J & Kemshall, H 2008, 'Social capital, resilience and desistance: the ability to be a risk navigator', *British Journal of Community Justice*, vol. 6, no. 3, pp. 5-21.
- Bolzan, N & Gale, F 2010, 'Care and control necessary theorising for social resilience', *Pathways to Resilience II: The Social Ecology of Resilience (7th-10th June)*, Dalhousie University, Halifax Canada.
- Bolzan, N & Gale, F 2011, 'Expect the unexpected', *Child Indicators Research*, vol. 4, no. 2, pp. 269-81.
- Bolzan, N & Gale, F 2012, 'Using an interrupted space to explore marginalised young people's social resilience', *Qualitative Social Work*, vol. 11, no. 5, pp. 502-16.
- Bottrell, D 2009, 'Understanding "marginal" perspectives: toward a social theory of resilience', *Qualitative Social Work, Research & Practice*, vol. 8, no. 3, pp. 321-39.
- Burns, J & Birrell, E 2014, 'Enhancing early engagement with mental health services by young people', *Psychology Research and Behavior Management*, vol. 7, pp. 303-12.
- Burns, J, Blanchard, M & Metcalf, A 2009, 'Bridging the digital divide in Australia: the potential implications for the mental health of young people experiencing marginalisation', in E Feffo, Y Dwivedi, J Gil-Garcia, & M Williams (eds), *Overcoming digital divides: constructing an equitable and competitive information society*, IGI Global, Hershey, pp. 90-111.
- Burns, J, Davenport, TA, Durkin, LA, Luscombe, GM & Hickie, IB 2010, 'The internet as a setting for mental health service utilisation by young people', *Medical Journal of Australia*, vol. 192, no.11, pp. 22-6.
- Chung-Chu, L 2008, 'The relationship between digital capital of internet banking and business performance', *International Journal of Electronic Finance*, vol. 2, no. 1, pp. 18-30.
- Cox, E 2003, 'A truly civil society (1995)', in D McDonald (ed.), *Boyer Lectures - Highlights 2: A meaningful democracy*, Australian Broadcasting Corporation.
- Craig, SL, McInroy, LB, McCready, LT, Di Cesare, DM & Pettaway, LD 2014, 'Connecting without fear: Clinical implications of the consumption of information and communication technologies by sexual minority youth and young adults', *Clinical Social Work Journal*, vol. 42, no. 3, pp. 1-10.
- Dominelli, L 2002, *Anti-oppressive social work theory and practice*, Palgrave MacMillan, New York.
- Eccles, JS & Gootman, JA 2002, *Community programs to promote youth development*, National Academy Press, Washington.
- Furlong, A 2011, 'Digital capital and inequality in late modernity', *TASA Conference (28 November – 1 December)*, University of Newcastle, Australia.
- Gale, F & Bolzan, N 2013, 'Social resilience: challenging neo-colonial thinking and practices around "risk"', *Journal of Youth Studies*, vol. 16, no. 2, pp. 257-72.
- Gerber, BS, Solomon, MC, Shaffer, TL, Quinn, MT & Lipton, RB 2007, 'Evaluation of an internet diabetes self-management training program for adolescents and young adults', *Diabetes Technology & Therapeutics*, vol. 9, no. 1, pp. 60-67.
- Hage, G 2003, *Against paranoid nationalism: searching for hope in a shrinking society*, Pluto Press, Sydney and Merlin Press, London.
- Hagell, A 2012, 'Health implications of new technology', *Association of Young People's Health (AYPH) Research Summary*, no. 11.
- Hsieh, H & Shannon, SE 2005, 'Three approaches to qualitative content analysis', *Qualitative Health Research*, vol. 25, no. 9, pp. 1277-88.
- Hough, A 2011, 'Student "addiction" to technology "similar to drug cravings", study finds', *The Telegraph*, 8 April, retrieved 18 June 2014, <www.telegraph.co.uk/technology/news/8436831/Student-addiction-to-technology-similar-to-drug-cravings-study-finds.html>.
- Kirmayer, LJ, Raikhel, E & Rahimi, S 2013, 'Cultures of the internet: Identity, community and mental health', *Transcultural Psychiatry*, vol. 50, no. 2, pp. 165-91.
- Klemm, DE 1986, *Hermeneutical inquiry*, Scholar's Press, London.
- Kuss, DJ & Griffiths, MD 2011, 'Internet gaming addiction: a systematic review of empirical research', *International Journal of Mental Health and Addiction*, vol. 10, no. 2, pp. 1-19.

- Löfgren-Mårtenson, L 2008, 'Love in cyberspace: Swedish young people with intellectual disabilities and the internet', *Scandinavian Journal of Disability Research*, vol. 10, no. 2, pp. 125-38.
- Mason, J 2002, *Qualitative researching* (2nd edition), Sage, London.
- Mathers, M, Canterford, L, Olds, T, Hesketh, K, Ridley, K & Wake, M 2009, 'Electronic media use and adolescent health and well-being: Cross-sectional community study', *Academic Pediatrics*, vol. 9, pp. 307-14.
- Matthews, H, Limb, M & Percy-Smith, B 1998, 'Changing worlds: the microgeographies of young teenagers', *Tijdschrift voor Economische en Sociale Geografie*, vol. 89, no. 2, pp. 193-202.
- Maurice-Stam, H, Scholten, L, de Gee, EA, van der Zanden, RA, Conijn, B, Last, BF & Grootenhuis, MA 2014, 'Feasibility of an online cognitive behavioural-based group intervention for adolescents treated for cancer: A pilot study', *Journal of Psychosocial Oncology*, vol. 32, no. 3, pp. 310-21.
- McGrath, H 2009, *Young people and technology: a review of the current literature (2nd edition)*, Alannah and Madeline Foundation, South Melbourne.
- Merry, S, Stasiak, K, Shepherd, M, Frampton, C, Fleming, T & Lucassen, M 2012, 'The effectiveness of SPARX, a computerised self-help intervention for adolescents seeking help for depression: Randomised controlled non-inferiority trial', *The BMJ*, vol. 344, <www.bmj.com/content/344/bmj.e2598>.
- Middaugh, J 2013, *Utilising social media to connect adolescents and young adults with hearing loss*, Doctoral Thesis, Ohio State University, Department of Speech and Hearing Sciences, Columbus.
- Moeller, S, Powers, E & Roberts, J 2012, '"The world unplugged" and "24 hours without media": Media literacy to develop self-awareness regarding media', *Scientific Journal of Media Education*, vol. 20, no. 39, pp. 45-52.
- Putnam, R 2000, *Bowling alone: the collapse and revival of American community*, Simon and Schuster, New York.
- Qvortrup, J 1994, 'Childhood matters: an introduction', in J Qvortrup, M Bordy, G Sgritta & H Lumtensberger, *Childhood matters: social theory, practice and politics*, Avebury Press, Aldershot, pp. 1-24.
- Sanford, S 2007, *Civic life in the information age*, Palgrave Macmillan, Gordonsville.
- Schneider, SJ, Kerwin, J, Frechtling, J, & Vivari, BA 2002, 'Characteristics of the discussion in online and face-to-face focus groups', *Social Science Computer Review*, vol. 20, no. 1, pp. 31-42.
- Shade, P 2006, 'Educating hopes', *Studies in Philosophy and Education*, vol. 25, no. 3, pp. 191-225.
- Raghavendran, P, Newman, L, Grace, E & Wood, D 2013, '"I could never do that before": Effectiveness of a tailored internet support intervention to increase the social participation of youth with disabilities', *Child Care Health Development*, vol. 39, no. 4, pp. 552-61.
- Sprod, R, Agostinho, S & Harper, B 2014, 'A social networking website that provides educational support to children living with type 1 diabetes', in H Tinmaz (eds.), *Cases on social networking websites for instructional use* (in press), IGI Global, Hershey.
- Steinfeld, C, Ellison, NB & Lampe, C 2008, 'Social capital, self-esteem, and use of online social network sites: longitudinal analysis', *Journal of Applied Developmental Psychology*, vol. 29, no. 6, pp. 434-45.
- The Starlight Children's Foundation (n.d.), 'What is Livewire.org.au?', *Livewire.org.au*, retrieved 5 June 2012, <Livewire.org.au/content/what-Livewireorgau>.
- Third, A, Kelly-Dalgety, E & Spry, D 2013, *Real livewires: a research report on the role of chat hosts in the Livewire online community for young people living with a chronic illness or disability*, Young and Well CRC, Melbourne.
- Third, A & Richardson, I 2010, *Analysing the impacts of social networking for young people living with chronic illness, a serious condition or a disability: An evaluation of the Livewire online community*, Young and Well CRC, Melbourne.
- Valentine, G & Holloway, SL 2002, 'Cyberkids? Exploring children's identities and social networks in on-line and off-line worlds', *Annals of the Association of American Geographers*, vol. 92, no. 2, pp. 302-19.
- Whittaker, R, Merry S, Stasiak, K, McDowell, H et al. 2012, 'MEMO – a mobile phone depression prevention intervention for adolescents: Development and postprogram findings on acceptability from a randomised controlled trial', *Journal of Medical Internet Research*, vol. 14, no. 1, pp. e-13.
- Young, KS 2009, Understanding online gaming addiction and treatment issues for adolescents, *The American Journal of Family Therapy*, vol. 37, no. 5, pp. 355-72.
- Young, KS & Rogers, RC 1998, 'The relationship between depression and internet addiction', *Online Psychology & Behavior*, vol. 1, no. 1, pp. 25-28.
- Zinck, E, McGrath, P, Fairholm, J, Contursi, ML et al. 2013, *Using technology to provide support to children and youth in challenging contexts*, CYCC Network, Halifax.

Appendix

ONLINE DISCUSSION QUESTIONS FOR LIVEWIRE MEMBERS:

1. Can you tell us about the different kinds of technology you use?
2. Do you have a favourite gadget to use, like a laptop or iPad? If you do, why is it your favourite?
3. How often do you use technology and what types of things do you use it for?
4. Do you use any special kind of computer programs to make using technology easier? If you do, how do they help you?
5. How would you describe a 'community'?
6. What do you think makes a good community?
7. Do you think that a community on the Internet is different to other types of communities?
8. Are things you do on the Internet also part of your life when you are offline? If yes, how?
9. Does where you live have anything to do with the stuff you do on the Internet?
10. Do you use the internet to find out what's happening around you?
11. Where do you use the Internet in your house?
12. Are there any rules about using the Internet in your house?
13. Does using the Internet mean you don't see many people in person?
14. Tell us about who YOU are when you're using Livewire and other websites. Do you see yourself differently on the Internet than you do offline?
15. What kind of things that you have created do you share on Livewire and other websites?
16. What kinds of computer programs do you use when you make and share your creations?
17. Do you like talking to other people about things you have made?
18. When you find a picture, video or story on the Internet that you like, do you send it to your friends so they can check it out too?
19. Do you ever create things with other people on the Internet? How do you do it?
20. Last time we asked about this you said... Is there anything you'd like to add?