



## Making connections: A capacity building approach to health literacy

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## **Making connections: A capacity building approach to health literacy**

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### **Abstract**

Participation in a series of Internet based projects has facilitated significant social benefits for community members marginalised by age, ethnicity, gender, geographic location and/or disability in a rural region of far north Queensland, Australia. The projects were underpinned by a belief that lack of access to information and social isolation can impact adversely on health and well being at both the individual and community level.

Outcomes from these projects challenge narrow approaches to health literacy. We draw on a framework of capacity building and empowerment that enables individuals to make informed choices and exercise increased control over their lives. Specifically, we describe the process used in these projects to provide access to information in an inclusive and supportive environment and, even more importantly, to create connections between individuals and groups that foster social inclusion. Such connections have provided vital ongoing channels for information sharing and social support that are critical to health and well being.

### **Introduction**

*The first Innisfail group included a number of people with visual impairments and they were looking for a new direction in life and for the confidence to move into a new area of work with a disability. Another workshop in Innisfail included a large group of volunteers from the local community centre. The coordinator is incredibly enthusiastic and always looking out for projects to enrich the local community. She has also identified a group of parents of children resuscitated at birth. We are currently setting up a workshop which will give this group both the skills and the opportunity to search the Internet for information, resources, and support groups relating to their children's needs. (Melinda Stockwell, Regional Coordinator, August 2004)*

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These two projects in Innisfail, (a small rural community in north Queensland's Atherton Tablelands), are part of a wider integrated series of projects that aim to deliver information and communication technology (ICT) training options to rural and remote areas of Queensland. But, as the anecdote makes clear, there is more than just skills training going on; participants are being empowered to gain new skills and confidence, form new networks, become active in the community, and be proactive in addressing their own health and well being needs. As the anecdote hints, separating individual and community empowerment from its influence upon health is not meaningful. While there are many definitions of community, this paper takes an interactional view of community: community as the interaction between and cooperation of people to solve problems and improve well being (Wilkinson, 1989). As Warschauer (2003, p. 47) notes, "... people become literate not just through physical access to books, but through education, communication, work connections, family support and assistance from social networks". Health literacy matters in community development, because community well being and health are so inextricably linked.

### **How we understand health literacy**

Health literacy has been defined both narrowly – in terms of the ability to read and comprehend health information (see for example the definition developed by the US Joint Committee of National Health Education Standards, 1995) – and more broadly. Nutbeam (1998), defines it as representing: "... the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (p. 357). Further, this implies "the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions" and that by "... improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment" (Nutbeam 1998, p. 357). Nutbeam's definition is an apt description of the development taking place in the Innisfail example cited above.

In this paper we consider the value of a series of carefully designed and implemented ICT projects for enhancing health and wellbeing in the broadest sense – whether their potential to build on and build up community capacity, and what health and well being benefits can be derived from such projects. Building on the social capital work of Putnam and others, Kawachi (1997) notes that "...public health also

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depends on a less widely understood influence – social cohesion” (p. 1). The above anecdote signals just such a link between individuals working together and sharing resources, skills and information, and better outcomes for health.

### **What makes a healthy community**

To reach a state of complete physical, mental and social well being, an individual or group must be able to identify and to realise aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasising social and personal resources, as well as physical capacities. (*The Ottawa Charter for Health Promotion, 1986*)

To try and separate community from its influence upon health is not meaningful. The term ‘health’ relates to far more than physiological well being, encompassing many components of psychological well being, such as sense of identity and belonging, sense of place, sense of safety and security, sense of connectedness to others, and feelings of trust (The Communication Centre, 2001). Health, then, also encompasses our social well being, for without having the capacity to interact positively with others, to contribute to the accomplishment of mutually shared goals, and to build commonly shared norms, physical well being is compromised. The quality and extent of social interactions are therefore important determinants of health at the individual level, as well as at the community and population levels (Baum, 1999; and see Kawachi, Kennedy & Glass, 1997).

Lee, Arozullah and Cho (2004) studied the connections between low health literacy, health status and service use. They note the social dimension of health literacy, finding that an individual’s socio-psychological circumstances influence the way health care is sought, and that “Tangible support from social networks may help those with low health literacy by reducing the stress of dealing with the health care system” (p. 1315). This supports Ratzan’s earlier (2001) finding that “communal activity and community sharing translates into better health” (p. 213). As well, social connections, group involvement and the associated levels of trust, have been correlated with better health outcomes (Baum, 1999). Preece and Ghazati (2001) reported on work that found that social networks played a role in “affirming, supporting, and rewarding good health practices” (p. 243). They also note that one way in which this occurs is via the provision of social and emotional support that helps to “... change behaviour patterns and encourage more healthy living” (ibid). Thus, “Residents in high trust neighbourhoods may also share more resources, be

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willing to help one another and offer one another more emotional support” (Ratzan 2001, p. 213).

Living in a community that is supportive emotionally and practically is likely to bolster psychological health, reduce levels of experienced stress, furnish practical aid in times of stress and ill health and will be more effective in mobilising health resources if they are wanted (Putnam, 2000). In addition, healthy individuals are better able to contribute to their communities, and so may be in a better position to develop social capital. There is also evidence that less polarised and therefore possibly more socially cohesive societies experience better health outcomes (e.g. Wilkinson, 1996; Ellison, 1999). (Feinstein et al., 2003, pp. 7-8)

Lee et al. (2004) consider that communication and transaction activities underpin social support and:

... serve a variety of emotional, informational, and tangible needs, all of which link to notions of information, uncertainty reduction, and personal control ... Emotional support promotes feelings of self-esteem, and self-confidence that enable one to accept and effectively cope with individual limitations (such as low health literacy) and their adverse consequences. (p. 1315)

They further suggest that “... the positive resources and support in individuals’ social networks can improve their ability to acquire and understand medical information and to negotiate the health care system” (Lee et al., 2004, p. 1314).

Effective community requires the inclusion of all community members. Social capital literature emphasises that “community life itself is sustained when social networks are strong, when there are people with common interests and who feel a sense of common fate” (Berkowitz, 1996, p. 452). Individuals from all sections of the community need to feel valued, regardless of the challenges they may face because of ethnicity, literacy, age, gender or disability. Effective community development encourages activities that build links which cross such boundaries. This implies that opportunities to benefit from education and training must be extended equally to all members of the community.

The absence or poverty of such social networks or connections, according to Graham (2002), “... limits a person’s ability to extend their influence in time and space, often condemning them to local, place-based ties and relationships. It undermines group, neighbourhood and individual ability to tap into and benefit from dominant technological and economic processes” (p. 53). This is increasingly important where health services or information are delivered via new technologies like the Internet.

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### **Health and community capacity**

A recent health survey in Queensland (Queensland Health, 2003) found that there were links between the core social capital dimensions of reciprocity and cohesion, community identity and generalised trust and good health behaviours. Labonte (2004) explicitly links these concepts of social cohesion to another term, community capacity, and draws upon the definition of community developed by Easterling et al. (1998): "... the set of assets or strengths that residents individually and collectively bring to the cause of improving local quality of life" (p. 12).

Taking this further, Bella and Bishop (p. 13) divide capacity building into building *on* capacity – "building upon the existing strengths and skills of community members" – and building *up* capacity – "bringing additional resources from outside". This is an extension of the concepts of development *of* community (including for example capacity building and leadership training) and development *in* community (including socially or economically focused projects) (Wilkinson, 1989). From a community development perspective, although both are important, it is argued that greater precedence should be given to development of community because it relates specifically to the process of community development, whereas development in community emphasizes locality as a setting for projects or programs. A development *of* perspective focuses on building the capacity of local people for community interaction to collaborate and work together to find solutions to local problems, and to determine shared objectives that contribute to the well being of the local community as a whole. Empowerment, or self-efficacy, is important here, as the Queensland health survey underlined: "Self efficacy, or a sense of control over the decisions which affect life, was a highly influential factor in the reporting of higher quality of life, better health and greater satisfaction with health" (p. 1).

Labonte and Laverack (2001) make clear the link between capacity building and health in their definition of capacity building as an "increase in community groups' ability to define, assess, analyse and act on health (or any other) concerns of importance to their members" (p. 114). Goodman (1998) also underlines the importance of capacity to health, noting that community capacity affects the "... ability to identify, mobilize and address social and public health problems".

Health literacy is part of this capacity. Bella and Bishop (2004) note that the ability to solve a problem, an element of Chaskin's definition of community capacity, requires literacy: "Investment in the skills, knowledge, and resources of individual

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residents can significantly enhance their ability to garner resources and improve their economic well being” (Bella & Bishop, p. 3). And Feinstein et al. (2003) found that learning itself (development of individual capacity) had health benefits: “Participation in adult learning has positive effects on a wide spectrum of health and social outcomes” (p. iii). In their studies of the wider benefits of learning, these researchers found that adult learning (at each of four levels – academic accredited, vocational accredited, work-related and leisure) has significant positive affects on health behaviours and on well being. Furthermore, these health benefits extend beyond the individual. In related research, Schuller et al. (2002) listed the benefits of learning as:

- Enabling people to communicate more effectively with professionals, and to formally and informally exchange health information
- Increasing self-awareness and self-understanding
- Strengthening social networks
- Triggering the virtuous cycle of learning and volunteering
- Generating further learning needs with benefits for “community development and neighbourhood renewal” (p. viii)

So, training that addresses literacy – including technological and computer literacy – also enhances health literacy, and in turn, health benefits to both individuals and to the community. Healthy communities are communities where individuals – including those on the margins – feel connected to a supportive network, and are empowered to seek and share information for the common good. If we are to help build such communities via training opportunities, these elements of inclusion, connectedness and empowerment must have a key role.

### **Why ICTs might help**

With governments internationally pushing towards providing services online has come research into how valuable the Internet may be for increasing social inclusion and networking, individual and community empowerment, and for enhancing community capacity. Three earlier projects (The Rural Women and ICTs Research Team, 1999; The Communication Centre 2001, Simpson et al., 2001)\* reported on the potential of ICTs for enhancing social networks and providing opportunities for supporting and empowering those living in rural and remote areas of Queensland.

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\* Now renamed the Service Leadership Innovation and Research Program.

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Technology in these projects is treated as “a means, and often a powerful one, rather than an end in itself” (Warschauer, 2003, p. 47).

However, policy often lags behind research and is not always evidence based or informed by research. Taking one example, the Australian Government’s *Health Online* project documents take a perhaps simplistic approach to the opportunities afforded by online service delivery, stating “The main concerns regarding access to information by consumers in rural communities relate to inequality in terms of the availability, cost and quality of rural Internet services” (NHIMAC, 2001, p. 74). While adequate physical infrastructure is crucial, the focus on such ‘hard technology’ ignores the social dimensions of health provision and engagement. Nonetheless, electronic access to government services (like the national health insurance deliverer Medicare) may reduce the sense of loss associated with the downgrading of shop-front services in remote and regional locations, and access to electronic conferences and workshops provides up-to-the minute information that could be applied speedily at ‘real’ community level. However, such online information needs to be digestible and understandable by the end user; users’ health literacy as well as the way information is presented – and where it is presented – are crucial to its value. These infrastructure elements have been described as the “social ‘soft technologies’ – the arrangements that determine [ICT] use, by and for whom, when, and at what cost” (Milio, 1996, p. 22).

ICTs provide opportunities for developing social connections and social infrastructure. An ongoing study by the Pew Internet and American Life Project has found that half the Internet users surveyed (n = 1690) reported that e-mail strengthened their family ties, and that Internet users reported more ‘robust’ social networks than non-users (Pew Internet and American Life Project, 2000). Barbara Peschiera (1999) also makes the point that “access to technology is now an essential tool for functioning in community”, and the adoption of computer-mediated technology can have profoundly positive outcomes if embraced wisely and judiciously by communities. This use of the Internet as a vehicle for enhanced social (including health and well being) outcomes is widely supported (see, for example, Rice & Katz, 2001; Ratzan, 2001; Balka, 2001; The Rural Women and ICTs Research Team, 1999; The Communication Centre, 2001, Simpson et al., 2001). The findings from one of the research team’s previous projects, ‘Enhancing Rural Women’s Access to Interactive Communication Technologies’ (1996-98 – The Rural Women and ICTs

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Research Team, 1999), for example, provide clear evidence of the ways in which communication technologies can facilitate the development and maintenance of social networks. This may be a particularly valuable outcome for older CALD\* people, in that Australian Bureau of Statistics (ABS) data (1991 census) reveal that people from diverse cultural and linguistic backgrounds are more likely to make use of home-based support services than residential services as they grow older. This trend suggests that enabling connection and social support via the Internet may be especially important for such groups.

However, a number of significant barriers to the use of this potentially valuable tool remain. Rice and Katz (2001) raise serious questions "... about the ability of those with economic, intellectual, or physical limitations to participate effectively in this new environment" (p. 6), and Loader and Keeble (2004) point out that:

The primary exploitation of ICTs has been overwhelmingly by the social, economic, cultural and geographically located groups and organisations that are already best connected, highly skilled and most able to organise and configure the shift online to their own advantage. (p. 7)

'Digital divide' is a term frequently used to describe the social implications of unequal access to ICTs and the resulting limited development of ICT related skills for some sectors of the community (National Office for the Information Economy, 2000; Simpson et al., 2001; Wilding, 2001). Recently, using 'digital divide' to contrast those who have access with those that do not has been challenged. There are a myriad ways that technology is accessed, usually woven into social systems and processes as part of social networks involving relatives, friends and colleagues. Grunwald (1997) notes that technology initiatives alone are not a panacea unless they are embedded in processes of community development, where the emphasis is not on the technology and what it can do, but on how the technology can be used strategically to meet community needs. The intent of policy then should extend beyond closing the 'divide' through mere access to technology, but instead focus on strategies that foster social inclusion, mobilise community support for achieving community goals, and thereby "multiply" the existing community assets (Warschauer, 2003, p. 47).

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\* Cultural and Linguistic Diversity

### **The framework**

As our previous work and the literature have shown, inclusion, connectedness and empowerment have key roles in building healthy communities. Health and well being and health literacy revolve around individual and community empowerment and capacity, and a sense of support and connection. In the framework we propose in this paper, ICTs have a role to play in this nexus, not simply because of the transfer of service provision to the Internet, but because – carefully implemented – ICTs may act as a tool for the facilitation of the empowerment, social inclusion, social networking and information sharing, and growing community capacity, that build health communities and individuals.

Over the past five years, QUT researchers have been involved in the development and funding of a series of collaborative community-university projects in regional and rural far north Queensland that facilitate online service delivery and support, all following the framework of inclusion, social connectedness and empowerment discussed above, offering computer and Internet skills training to communities in rural and remote north Queensland. In the following sections, we introduce the projects and look at how they are contributing to health literacy and to health and well being.

### ***Preamble to the projects – the rural and remote context***

Rural and remote populations often experience poor access to services (Simpson et al., 2001; Wagenfeld, Murray, Mohatt & DeBruyn, 1997). This applies to essential health services, to services that enable individuals and communities to gain the skills necessary to participate in the social changes affecting the population, and to the peer support services needed by isolated professionals. In Australia, longstanding factors in service delivery to rural communities, such as sparse population, distance, and limited availability of public transport, are being exacerbated by the reduction in and withdrawal of existing face-to-face services. Access to services and support is no longer available through traditional service delivery modes. In terms of health services, access constitutes a significant issue for rural communities, as the following quote shows:

*I've travelled probably twenty times to Brisbane and Toowoomba, and there's nobody out here that can help me. No doctor. ... There's nobody up here. And [the specialists] come once every six months. 'Oh, can you wait for the paediatrician to come, they're coming in December'. No, I can't wait, like, we need your help now ...' (fieldwork, June 1999).*

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At the same time, the traditional jobs base for these communities in primary production is shrinking, resulting in the need for re-skilling of many of those people formerly employed in such industries.

As our introductory anecdote showed, health literacy – understood in its broadest sense – is a key issue for these communities. As Parker (2000) notes, “... for those with limited health literacy, as health care is becoming increasingly complex and health information is becoming more diffuse in the public domain, there is more reliance on written materials to educate and inform people about their health” (p. 280). As governments at all levels seek ways to simplify – and reduce the costs of – the task of meeting health service needs, the attractions of e-government for service delivery to a receptive ‘wired’ community are strong (and ICT vendors have certainly encouraged that attraction). However, for those community members used to the supportive environment of face-to-face service delivery, and unfamiliar with ICTs, the focus on service provision via the Internet creates new challenges. This push, together with the social changes mentioned above, means that the incentive for computer literacy (noted by Hamm, in Loader & Keeble, 2004) is strengthening.

Remoteness and other factors exacerbate the issues of health literacy. The problems associated with negotiating the changed rural social and service environment impact particularly upon those people who have characteristics which may intensify their isolation and lack of access to information, including people of cultural and linguistic diversity (CALD), disabled people, and people with low literacy skills. These groups were noted by the project coordinator to be those most consistently excluded from other programs on the basis that they are ‘unteachable’, ‘too hard to deal with’, and ‘take up a disproportionate amount of the teacher’s time with very little to show for it’. As discussed earlier, a socially inclusive society requires informed communities that have the means, the skills and the opportunities to communicate (IBM, 1997). For those unable to meet these criteria because of age, ethnicity, disability, income or circumstance, difficulties associated with the acquisition of everyday information via the Internet can potentially create considerable frustration and distress, increasing the degree to which they are marginalised within their community, and impacting on their health and well being.

### **The Case Study Projects**

This paper reports on a series of completed and ongoing projects in rural and remote Queensland, building on earlier work which identified the difficulty in accessing

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accurate current information and in obtaining appropriate support to health and well being for these populations. To take a health-related example, interviewees in fieldwork for *Creating Rural Connections* (Simpson et al., 2001) reported a variety of information needs, including more timely access to a wider range of information, and the desire for specific information in response to an identified need (such as to address a health problem), to locate employment, or to improve the family business:

*We're always hungry for information because we don't have a regular newspaper and we don't have a regular magazine or anything like that ... But if we could find information that we need quickly — you could look up at least 'Oh look here you can find something about measles!' You're not so isolated are you? You could just say, 'This is this and these symptoms are quite normal and these symptoms aren't' or something like that. You don't feel like you're a hundred miles from the doctor. (audioconference, October 2000)*

Community members had identified two levels of specific need. First, the need for access to specialist services, including medical services and counselling, ongoing access to help, companionship and mentoring, community services databases to facilitate better networking and referral services, improved access to services for disability groups, particularly services that have the potential to overcome the effects of communication limitations and personal isolation, and opportunities to identify and reinforce existing support networks. They also identified the need for re-skilling, regarding computing skills as a necessary tool in the changing work and social environment. The projects developed to help address these needs – the Tablelands Older Women's Internet Training Project, **TaSS.net**: Tablelanders Sharing Skills through Online Networks, and **Building up the Bush**: Building strength in Tablelands Community Organisations – have provided an inclusive and supportive environment in which individuals who had experienced marginalisation of various degrees in their communities. The focus in each project has been on Bella and Bishop's (2004) "building on" community capacity: "helping people believe in their own skills" (p. 13).

### How the projects operate

Improving health literacy was not a specific aim of these projects. Rather, they built on the recognition that social isolation and access to information are significant issues for marginalised people in far north Queensland and, in particular, for people who speak little or no English, for Indigenous peoples and disabled people. Drawing on research that has shown the Internet to be an effective, appropriate means of meeting

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such needs for a diverse range of people (The Communication Centre, 2001; Simpson et al., 2001) the projects sought to:

- enhance the skills base in small communities,
- help create a more informed community, and a more equitable society in part via access to information by marginalised groups,
- facilitate the sharing of skills through the development and creation of online and face-to-face social networks,
- develop an innovative and transferable process that will be relevant to other groups and other communities,
- increase awareness of the potential of online technologies for contributing to the social connectedness and overall well being of potentially marginalised groups, particularly but not exclusively in rural and remote areas, and
- provide ‘Train the Trainer’ instruction for volunteer community members from marginalised groups that will assist them to conduct training that is appropriate for their client base, taking into account the specific needs arising from age, gender, rurality, ethnicity, literacy and/or disability.

While these aims focus on the technical and training needs of people in rural and remote communities, it is how these goals are enacted that creates the powerful social and health outcomes of the projects.

As we have seen, there are links between the development of these individual and community capacities (soft technologies) and better health outcomes. Projects intended to deliver ICT training to marginalised groups have often failed. When asked what the problems were with computer training programs they had attempted, participants identified the following:

- Modules not relevant to their needs
- Training moved too quickly for them to keep up with the group
- Couldn’t understand the trainer
- Class sizes too big
- Felt alienated from the other students
- Felt alienated from the teacher
- Too old
- Left it too late

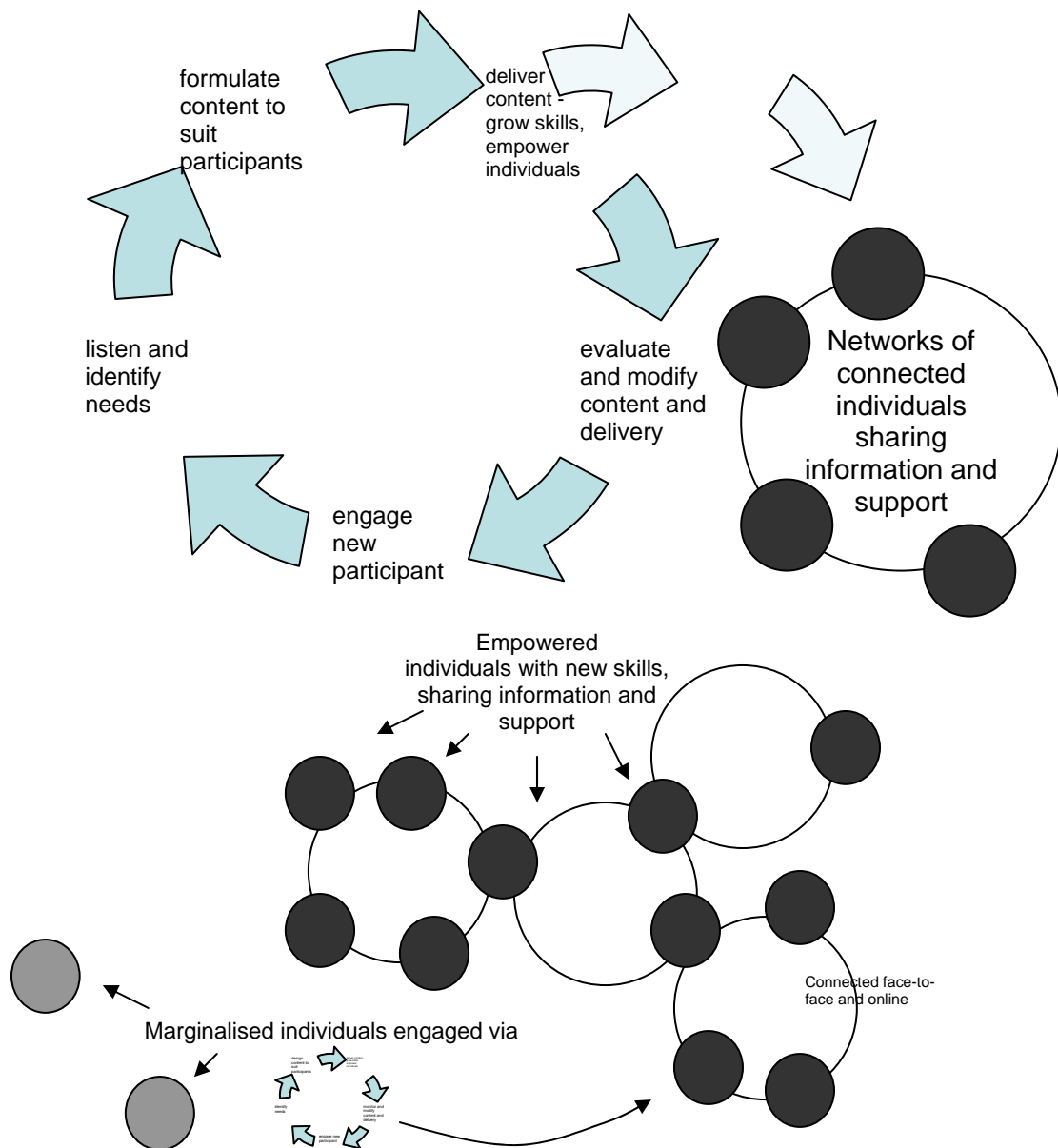
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As Feinstein et al. (2003) found, for those who have been away from learning for some time, there are particular qualities in the learning environment that enable the wider benefits to flow. Such programs need to “ensure engagement and classes that are not sensitive to learners’ needs are not necessarily going to generate the wider benefits. The provision of facilities and encouragement for interaction would also appear to be essential components” (p. 74).

The projects described emphasise the need to surmount these issues, and for building supporting and sustaining social infrastructure. LIFE cycle is methodology common to all these projects.\* LIFE cycle revolves around a four-stage approach (illustrated in Figure 1):

- Listen to the learner;**
- Identify the need/s;**
- Formulate effective programs; and**
- Evaluate and modify.**



**Figure 1: Inclusion, connectedness and information sharing – making connections face-to-face and online**

\* Workers delivering training refer to the process as “normal mode”, a label that downplays its exceptional and innovative qualities.

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- Engaging the marginalised

Engaging the community and ascertaining their training needs is the crucial first step. Tutors seek opportunities to publicise their programmes through community places like hotels, community centres and shops, as well as recruiting clients via other organisations in the community, which refer people with literacy and/or numeracy needs to the program, and also offer services to learners taking part in the program. This approach has resulted in participants from the majority of the identified marginalised groups, with no participants excluded from the projects. Three participants have been over 90 years old and many have been over 80, and there have been numerous participants from CALD groups.

- Listen

Developing effective strategies for access and participation that take differences in community needs and the whole range of local social, economic, cultural and technological factors into account can provide more equitable access to ICTs. Such an approach can also increase the overall sustainability and success of community informatics initiatives (Simpson, 2004; Simpson et al., 2001; The Rural Women and ICTs Research Team, 1999). Providing an environment in which participants feel they are valued, and are treated as capable equals, is crucial to LIFE cycle's first listening stage. Such inclusion and empowerment are even more critical requirements for those who are disadvantaged in terms of accessing the usual sources of computer training, such as older CALD women, or men and women experiencing upheaval in their working or family lives. Empowerment is important for, as Feinstein (2002) found, "Psychological well being, which encompasses a sense of personal control, and freedom from stress and hostility, in turn appears to lead to better health outcomes" (p. 9).

Some key descriptors of the initial part of the programmes hint at the way empowerment and inclusion are facilitated. Very early in the training, participants are left to their own devices to complete necessary forms and other documents; the tutor leaves them to "help yourself and each other". This is intended to give participants the opportunity to show what they can do, and to learn that they can trust and benefit from working with other participants, forming the start of potential networks. This step also seeks to demonstrate to participants that they have shared needs, that they can gain by working together, and that their own experiences and needs are valid.

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- Identify

In this environment, specific training needs can be accurately identified, since participants gain a sense that they are valued, that their needs are unlikely to be ‘way out’ or in some way unacceptable, and that their contributions and concerns will be treated with respect. Tutors encourage participants to use the technology to follow their own interests in the belief that something that has direct relevance to their own life will be more enjoyable, more relevant, and will enhance the internalisation of the learning process. Tutors also believe that this will generate more enthusiasm from participants than working through a set of pre-determined exercises.

- Formulate

The next step, developing effective programs, draws on the expressed interests of the participants. For example, participants might express a desire to be able to e-mail a friend or relative overseas, or to access a particular web site or support group via the Internet. The learning is therefore structured around this need. The structure of training often follows a series of specified guidelines and is intended to provide all participants with skills in basic computing skills and connectivity.

There are both accredited and non-accredited schemes in operation. In the non-accredited training programs, material is taught in a flexible self paced delivery mode. Participants are encouraged to attend each session but are not be penalised for not doing so. Emphasis is on meeting the learner’s needs. Feinstein et al. (2003) found that the particular value of unaccredited courses is that they “may equip adults with the personal and social confidence as well as other necessary skills to progress to more challenging accredited courses, especially if appropriate guidance is available” (pp. 76-77).

- Evaluate

In the projects in north Queensland, opportunities are provided for trying out the new skills, enabling the teacher to evaluate and modify the training. Is it working? Are participants moving towards confidence and facility?

***Outcomes – health literacy is much broader than simply putting the technology in place or providing the information.***

**The findings**

In our introductory anecdote we saw how the apparently straightforward provision of computer and Internet training had changed health literacy and health and well being outcomes for two groups living with disadvantage. Feedback from participants credited the tutors with much of the success of the programs. The following comments are typical of those submitted on feedback forms distributed by the coordinator:

- *Such wonderful teachers*
- *My tutor was very good and patient with me and was excellent.*
- *The ladies were very easy to work with and were very helpful!*

Volunteer tutors, drawn from a pool of individuals trained in LIFE cycle projects, form an integral part of the programs, mentoring learners both in and outside of class times to help them meet personal literacy goals and to complete their assessment tasks. Experiences from their training are crucial in giving these volunteers the capacity to empathise with new participants and to provide support. Some interesting broad qualitative outcomes of the projects include:

- CALD clients faced severe opposition from their families when they revealed that they were learning to use the Internet and e-mail.
- Women over 60 were the most hesitant to join programs.
- Once they joined the program, women over 60 attended more hours of training per week than any other participant group.
- No difference in the progression rate of participants from the different target groups.
- Clients failing at other computer training programs needed only 3 to 6 hours of individual tutoring to enable them to progress with confidence.
- All participants wanted to learn Internet and e-mail, although none of them requested this initially.

**Inclusion**

Health and well being outcomes are enhanced for previously marginalised individuals by the development of social connections; levels of integration within communities

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(reflected in access to child support, language training for those of CALD backgrounds, and job referrals) are known to influence the overall health status of the population (Simpson et al., 2001). The projects have provided an inclusive and supportive environment for people who have experienced varying degrees of marginalisation to expand and strengthen their social networks. For example, one class included two Indigenous Australian women, a woman from Papua New Guinea who is also physically disabled, a severely disabled man with spina bifida, a Spanish speaking woman from Honduras and a woman from Japan, a Cambodian man from the local Hmong-speaking community, two teenagers who were early school leavers (one of whom is mildly intellectually impaired), and several other participants who had received little or no formal education.

Participants gain the opportunity to address problems of social isolation and lack of access to information both through the classes themselves and the social contact afforded by them, and through a broadened range of online social contacts. The project coordinator highlighted this point in a progress report:

*Participants [have] set up their own e-mail addresses and we will continue to use e-mail to help the group to maintain contact with each other and with their new contacts overseas. We [have] also had a scanner set up and encouraged participants to bring in photos to scan in and e-mail to family and friends in other places.*

The tutors' experiences underline the strongly inclusive nature of project activities, as they report that these heterogeneous classes quickly form a character of their own and a strong sense of 'belonging' and 'group identity'. In many cases, groups never actually disband. Tutors give examples of participants becoming firm friends after meeting in class, and electing, for example, to spend Christmas together. Both tutors and learners often say that they look forward all week to coming to class, and "being with everyone".

The projects also confirm the importance of addressing social isolation through face-to-face interaction with others in the local community. For the women in the Tablelands Older Women's Internet Training Project, the interaction became an integral part of the learning experience. As one participant said:

*I've never had so much fun. I couldn't break into the community before. We come to tutoring with the other ladies — I look forward to it all week.*

And a tutor reports on inclusion that spreads beyond the immediate class group:

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*Morning tea has become quite an event as women who are not under taking training on that day often come in for a chat and to see how the others are getting on. Those with children often bring them at morning teatime, creating a family atmosphere. The participants have also begun to celebrate each other's birthdays. The first was Grazia, a recent migrant from Italy. Grazia was delighted and surprised, as her almost non-existent English skills previously precluded her from becoming involved in informal friendship groups like this.*

### **Empowerment, social support and information sharing**

Empowerment is crucial to Bella and Bishop's (2004) notion of building *on* capacity. Many participants start the classes with extremely low levels of confidence in their abilities, and this has impacted on their well being. They are reluctant to seek job opportunities or even to pursue training, and are often unable to source health information or support or do not have the literacy skills to take advantage of resources. Very early in the first training session, participants buoyed up by the supportive, inclusive environment, often reveal to the trainer, "in front of the class, that they are worried about their lack of education, and that they don't really think they should be there".

Empowerment means that once participants meet their initial learning goals they start to look to other possibilities, often involving further study, or ways of increasing access to the sorts of information or contact they value. One participant enrolled in a computer hardware course and is completing this simultaneously with CNLITNUM (Course in Adult Literacy/Numeracy, a basic, generic course well suited to the many needs of community adult literacy students) with support from their tutor. A second has enrolled in a basic computer course, another plans to enrol in a Certificate of Childcare, and two others are planning to undertake a creative writing course with the aim of writing professionally. A number of participants become actively involved in their community, through volunteer work, by seeking positions on local committees, and through the publication of a weekly newsletter; this both showcases their work and gives them a "voice in print", to quote one participant. Participants have also written to local newspapers voicing their concerns over a number of local issues, and written to local businesses suggesting strategies to help them better meet the needs of disabled and disadvantaged people in their community. And several have trained as volunteer tutors, and are now sharing their skills in a number of Atherton Tablelands communities. Those identified and invited to complete accreditation in Assessment and Workplace Training are representative of

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Indigenous people, older women, older men, young women, people with a mild intellectual impairment, people from remote communities, people from CALD backgrounds, unemployed people and people seeking a new direction in life.

Such outcomes, in terms of the opportunities participants feel able to tap into and initiate, have clear implications for the capacity of the community and of individuals to increase their health literacy, and maximise their health and well being. Lee et al. (2004) reported that “To the extent that social support is useful for coping with individual problems, health literacy takes on a social dimension, and the support and resources available in social environments should be considered as potentially important factors for alleviating the adverse effects of low health literacy on health outcomes” (p. 1311). As we saw in our initial anecdote, participants in the projects gain significant support:

*Having a safe place to try out the new technology. It has been very valuable, because we've all of us made some mistakes, we've all sent a message five times or forward to sender, or whatever, but there's been no criticism. There's been only support. And with that support has come confidence.*  
(quoted in Lennie, 2002, p. 301)

The safety alluded to in the above excerpt extends into the online environment. Researchers have suggested that one added advantage of utilising communication technologies for support is that users can discuss issues that are sensitive, or that they are reticent to discuss in a face-to-face setting (Spielberg, 1998). This predicted benefit was supported by rural participants, who highlighted the degree of anonymity provided by online support:

*... I think that email support groups are probably the most beneficial. You're talking to someone that you don't know, so you tell them the whole thing, and they're happy to just tell you what you should do, and whether you take it up or not is your worry, rather than someone being there, and it's a friend of yours telling you what you should be doing and how you should be doing it.*  
(fieldwork, June 1999)

These social networking and support outcomes may be particularly important in terms of health outcomes for participants experiencing significant life change and seeking out ‘lifeboats’ to help them through this period. The project coordinator noted that in some cases, participants see the courses as an available alternative to counseling services that are impossible to access in rural and remote communities.

### **Conclusions: The projects, health and health literacy**

The focus of these north Queensland projects has been on community ownership and community engagement. At the same time, the projects are linking participants

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directly into other communities and the world at large through ICTs, helping build stronger communities and actively engaging a wide cross section of people. Some individual stories are valuable here.

*Janet\* and her husband had just started a business and mortgaged their house to do it when a cyclone came through [Town] and flattened both. The new business could not recover from such a devastating blow. They closed down the business and lost their house. They have three small children. Janet was directed to the program by her doctor when she threatened to go under with depression. She came in first to do the volunteer course, became a literacy volunteer and with the help of a tutor completed grade 10 through TAFE. She then started a Certificate III in Childcare the following year. She continued to volunteer her time as a literacy tutor and the program provided her with a higher level volunteer tutor to help her with her Cert III. She finished that, then enrolled in James Cook University B Ed, still under treatment for depression. Janet loved the B Ed, remained as a volunteer for her first year and again we provided a tutor for her. In her second year Janet came off the pills and the family decided to move to Cairns so that she could study full time. Her husband looked after their children and Janet still received help from one of our tutors. Janet has now finished her degree and is the breadwinner. Janet's husband is minding their children and building his business anew without the pressure of having to provide for the family immediately. Janet remains active in the program and has not relapsed.*

*Barry suffered from depression after a serious accident in Thailand, where he had been employed as an ESL teacher. He was sent to us to "Do what he could and be with people". We felt some of the problem was loss of status and his job being no longer relevant. He liked the program, started tutoring and was great. I encouraged him to do Certificate IV in Assessment and Workplace Training to make his work experience current. To do this he needed to reduce his medication, so he set himself a goal to start in 6 weeks time. 6 weeks later he was back but doubtful. He had several months of false starts then suddenly took off and finished his Cert IV within the month. His presentations were so successful that one of the participants told her boss and she offered Barry a job. Barry came off the rest of his medication over the next 4 weeks, pronounced himself cured, moved to [Town], and took the job. Barry still remains active in the program and 15 months later has not relapsed.*

*Anne had polio as a child and was partially crippled. She had trained as a nurse and worked all over the world, mainly with aid agencies. When she was hit by post polio syndrome it was like the final straw. She was referred to our program from the pain management clinic.*

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\* All names have been changed to protect privacy.

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*Anne learnt to use the computer, completed her Master's in Tropical Health from home – travelling to the uni when she could. By the time she had finished, her post polio was too severe for her to move to outback Australia where she had planned to work. She trained as a volunteer tutor, was great and our program funded her though Certificate IV in Assessment and Workplace Training. She met people in the program who were doing an art course so she enrolled and, at the end of year display, sold all her paintings. She continued as a volunteer tutor, and was encouraged to look for a job in this area. After broadening her employment choices she got a job as a baby health sister in [Town], where she is doing a wonderful job. She continues as an active participant in the program.*

Progress is being made, then, towards more equitable and socially inclusive communities. It has been critical for those people previously marginalised by illness, disability, literacy and/or linguistic or geographical isolation to participate in the information age to avoid the possibility of further exclusion. As well, there are economic benefits from an increased skills base:

*Many men who have been labourers or worked in physical areas and who have been injured and expected to be on compo [workers' compensation] for the rest of their lives have come into the programmes. They have discovered they like teaching, completed Certificate IV in Assessment and Workplace Training and have gone back to train in their previous areas of expertise. One here today was a chainsaw worker, others worked in forestry, the building trades, fishing, etc.*

These are individual cases where the projects have lead to better health – and well being – for participants. As well, as our introductory anecdote about health support groups shows, participants have become proactive in seeking and sharing health information and support. Social networks have deepened or extended and marginalised individuals now have the opportunity to participate and more readily share their experiences:

*Svetlana was able to access and read her home town newspaper in Russia; Vera, a Spanish speaking lady, found two recipes of her grandmother's, which she told us had been lost for two generations; and Sandy and Ros couldn't be torn away from chatting with a group of women in America for over two hours.*

Outcomes from these projects challenge narrow approaches to health literacy. Improved health literacy was not the aim of the projects, but processes that focussed on bringing positive changes in levels of social inclusion, empowerment, social networking and information sharing have led to better health and well being outcomes. The projects' framework of capacity building and empowerment enabled previously marginalised participants to make informed choices and exercise increased

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control over their lives. Specifically, the process used in these projects provides access to information in an inclusive and supportive environment and, even more importantly, creates connections between individuals and groups that foster social inclusion. Such connections have provided vital ongoing channels for information sharing and social support that are critical to health and well being.

The wider communities have also experienced change as a result of the projects. With reduced depression, increased skills, social contacts and confidence, individuals whose capacities had been effectively lost to the community have been re-activated, building community capacity. As well, opportunities for further education (and the built *on* capacity to exploit such opportunities) give the immediate community, and communities in the wider area, greater capacity as well as income.

As well as creating a growing number of volunteer trainers, spreading their new skills to an ever wider pool of learners, other computer training projects with older people have stimulated community enhancement activities such as initiating and running seniors computer clubs, and other community ICT access projects further afield.

### ***Principles for community workers***

These projects were not designed with improving health outcomes in mind; instead they focus on increasing the skills base in rural and remote communities. However, they have demonstrated a clear link between increased social cohesion and connectedness, health literacy and health outcomes. While the broad aims of the projects are perhaps not exceptional, the LIFE cycle way of working – “normal” mode as the workers call it – is. LIFE cycle is characterised by extreme flexibility and fluidity: from holding classes in settings and at times that suit the learners, to the recruitment of participants in unconventional ways and places, to the formulation of content to fit the needs of participants, these projects deliver bounded objectives in almost completely unbounded ways. Just about anything goes, and the trainers happily throw out or embrace material according only to whether it is appropriate to the participants’ requirements and capacities. Four crucial aspects of the LIFE cycle approach are:

- Participation and inclusion

The equitable and inclusive participation of people in planning, evaluation and decision making is vital to sustainable community and economic development. The

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programmes are specifically targeted to marginalised individuals, with the trainer taking a proactive approach to inclusion. This group is often the most reluctant to ‘sign up’, and tend instead to be referred to courses by agencies (including community groups, government bodies and agencies, and others organisations such as schools, special interest groups and welfare groups). The various capacities and experiences of participants are overtly valued and celebrated, with trainers and other class members supporting and empowering one another in an encouraging, inclusive environment.

- Content

It is crucial that content is individually tailored in a group setting to the needs and interests of the clients, is culturally sensitive and gender inclusive, and is made accessible by attention to the language and literacy needs of specific groups within the community – such as those from CALD backgrounds. Hence, courses are designed around what participants want, using real life learning needs or desires to shape learning delivery:

*When the participants turned up the trainer and volunteer asked what they wanted/needed to learn. One wanted to trace his shares so they scrapped the lovely bound manual I had given them and pulled out an excel manual from the supplementary materials I had also supplied. That participant shouldn't have learned to use the computer on an excel spreadsheet learning to list and update his shares, but why not? (Melinda Stockwell, regional coordinator, August 2004)*

- Delivery

Delivery must be flexible and responsive to learners' needs, incorporate design features that capitalise on the tools made available by evolving communication technologies, and support access by people with varying levels of ability, including those with mobility, vision, hearing and cognitive difficulties. In designing training delivery projects, differences between people therefore need to be taken into account, including gender, age, ethnicity, occupation and level of knowledge of new technologies.

- Time

Allowing sufficient time for the development of the positive attitudes and skills necessary for the effective adoption and utilisation of online technology is important. For example, the need for ‘hastening slowly’ is evident in each of the human factors affecting the acceptance and value of web-based services (The Communication Centre, 2001). Taking this into consideration, some courses are self-paced, allowing participants to work through individual modules at their own pace, and with the

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support of peers, tutors, family or friends. This flexibility allows for work and family commitments and allows participants to work around farm and seasonal commitments.

In conclusion, Nutbeam's (1998) definition of health literacy included notions of "the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions" and that by "... improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment" (p. 357). A final anecdote underlines that just such effects have flowed from these projects:

*I did all of those activities on Day 1 and it really opened my eyes. On Day 2, I listened to everything you said about valuing ourselves, we can always do more than we think we can, trusting and valuing our own skills and abilities, not being afraid of failing and giving it a shot. I decided to trust you, and went home and did what you said. I had no job, I was going to lose my house on Friday and my girlfriend was leaving me because I wouldn't commit. How could I when I had nothing? I saw a great job at QML in the paper, heard your voice and applied for it. I got the job 5 days later and went to the bank and re-financed my house. Then I asked my girlfriend to marry me and she said yes. I have a whole new life after 3 weeks, but unfortunately I have to quit the class!"*

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