

APPLYING MEDICINE 2.0 TO THE I-CAN

Managing the Needs and Rights of End Users

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Abstract: This paper considers how Medicine 2.0 features can be added to an existing e-health application known as the I-CAN (Instrument for the Classification and Assessment of Support Needs). One of the biggest problems with a social networking feature based around health concerns is the issue of privacy. Even though participation is on a completely unsolicited, opt-in basis, there are access and privacy issues involved in such a tool. A preliminary design proposal is presented which takes into account the needs, responsibilities, rights and abilities of the (direct and indirect) users.

1 INTRODUCTION TO I-CAN

I-CAN do it! That is the motto of the Centre for Disability Studies (CDS) Instrument for the Classification and Assessment of Support Needs (I-CAN) (Llewellyn et al. 2005). Since 1998, CDS and partners have been developing a tool to assist support services to determine the current and future support needs of people with disabilities (Luckasson et al, 1992). The I-CAN evolved into a web-based assessment tool in 2007. Adding a web-base to a pen and paper psychometric assessment allows many new possibilities, including more sophisticated data gathering, data management, scoring, reporting, monitoring outcomes, costing and other e-health applications. The I-CAN offers an efficient way to manage and appraise individuals' support needs.

The current I-CAN version 4.2 (Arnold et al. 2008) was released October, 2008 now using completely web based software. It was developed using Linux, Apache, MySQL and PHP (LAMP) and is available online at <http://www.i-can.org.au/>. The current target group for this software is community support services or government departments that want to assess data relating to the needs of people with disabilities. These services can

purchase access to the system and do the assessment online. A brief version of the assessment tool focused on individual funding has been recently developed. Furthermore, CDS offers hard-copy manuals and facilitator packs, face-to-face training sessions, a data entry service, telephone, and email support for their customers. It is hoped online and video training resources will also be developed.

I-CAN identifies the areas in which support is needed in the current and/or future environment. The higher level domains, based on the ICF, comprise Health & Well Being and Activities & Participation in daily life. The items within each sub domain, shown in blue in Figure 1, are rated according to the frequency and level of support required. Needs are balanced on support important to and important for a person, with a focus on the person's long term dreams and goals. The resulting support for the person with a disability is seen as a means to engagement, empowerment, and inclusion for a life of quality.

I-CAN is designed to be used across disability types and levels of impairment. It focuses more on the support needed than on deficits or skills. The trained facilitator, together with the person with disability and key people involved in that person's

life complete the assessment and decide on future support activities.

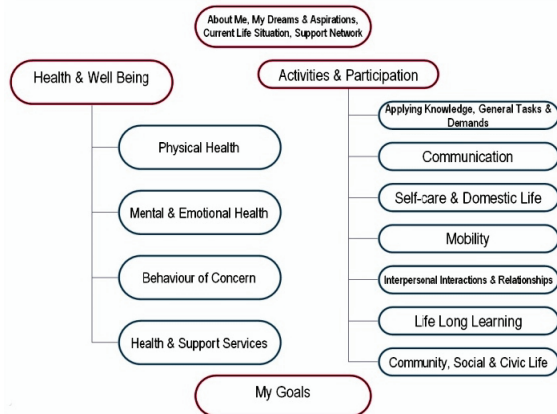


Figure 1: Domain structure of the current version 4.2 (I-CAN 2008).

Web 2.0 has enabled the average person to connect and communicate. The many social benefits provided should also be accessible to persons with disabilities. To that end, this paper proposes that Web 2.0 technologies can be applied to I-CAN but identifies that privacy, security and access issues become heightened due to the nature of the domain, data and the user. Before looking at those issues we consider the current functionality of I-CAN and the limitations to be addressed.

1.1 The Functions of I-CAN 4.2

Support services enter personal data of the person with disability into the online system either directly during the interview process (Figure 2) or afterwards with the help of the pen and paper data recording form that can be used if there is no Internet access available. The data are stored on the I-CAN server where each support service has limited access to their section of the database, with further access restrictions based on organisation departmental sub groups.

I-CAN Health and Well Being - Mental and Emotional Health

Is this section applicable? Yes No - N/A

Mood: varying mood agitation / irritability depression - crying, upset withdrawn bipolar disorder other... please specify

Frequency of Support: Never no support required Occasionally support required less than once a month Monthly support required 1-3 times a month

Figure 2: Screenshot of I-CAN data entry form (I-CAN 2008).

After the support services enter the personal data they can generate individual support needs reports for any person using different document formats (mht, rtf, doc, etc.). This report is similar to a comprehensive discharge report, and has been used for discharge and intake assessments. The report is automatically generated by the website, and there are also additional options to download only summarized reports and task lists. The report shows a qualitative Support Needs Breakdown, About Me and Current Life Situation, etc. Statistical graphs (e.g. Figure 3) show domains where support is needed. These graphs can be used for classification, comparison, monitoring change over time and measuring outcomes. The photo upload function allows the support services to upload pictures of the people they support and generate a more personalised report.

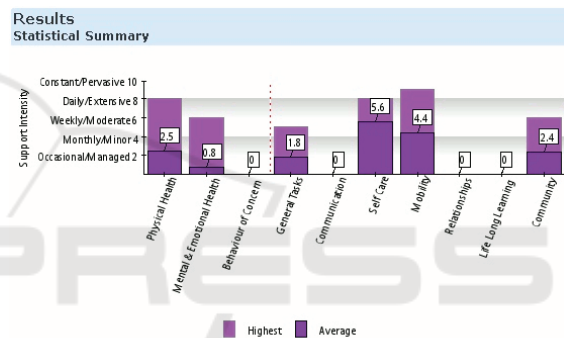


Figure 3: Highest and Average Support Intensity

Figure 3: Statistical Summary of domain Support Intensity (I-CAN 2008).

The personal data can be edited and small updates entered into the system as needed. There are often changes in a person's life circumstance, health and skills that result in changes in support needs. These changes are tracked on the system, so it is possible to monitor the development or decline of each person over time and to predict possible future support needs. The cost estimation function calculates costs of providing services based upon the actual formal services needed and award salary rates. The outcome is an Excel worksheet (Figure 4) that allows adjustment of on-costs and other organisational costs to predict the costs of service provision more accurately within the particular setting.

| I-CAN Cost Estimation | | NSW SACS Employees (State) Award 12/8/06, HSU Residential Care Assistant | | | | |
|-----------------------|--------------|--|-------|--------|--------|---------|
| POSITION | YR | Hours | BASE | ONCOST | TOTAL | PERCENT |
| CSW | Grade 1 Yr 1 | | 14.72 | 3.88 | | 100% |
| CSW | Grade 1 Yr 2 | 7 | 15.28 | 3.82 | 133.70 | 100% |
| CSW | Grade 1 Yr 3 | | 15.84 | 3.96 | | 100% |

Figure 4: Outcome of an I-CAN cost estimation (I-CAN 2008).

1.2 Current Limitations of I-CAN

In the current version I-CAN 4.2 only support services have access to the system. This is a requirement for some services, e.g. government departments who may use the system to determine individual funding resource allocation, or in forensic cases, that require strict access control and procedures. However, this limited access is problematic for some organisations using the I-CAN and limiting for some people with disabilities and their families. The purpose of I-CAN is, among others, to encourage and empower people to be active members of society. This includes actively taking part in their health care and their support service arrangements. Currently, the participation of persons with disabilities and their family members/friends in I-CAN is limited to answering questions during the typically annual semi-structured assessment and interview process.

Currently the person with disabilities benefits passively from the system. They get a better support service because the health and support professionals have more detailed information about the persons' needs and how the person wants to be supported. The question is, how can people with disability and/or family members and friends be more involved in I-CAN and benefit actively from the tool outside of the annual interview process?

The answer to this can be found in Web 2.0 technologies and the possibilities for users to create content. Medicine 2.0 is a term used to describe Web 2.0 technologies in combination with e-health applications. According to Pagliari and colleagues (2007) there is a mounting demand for flexible access to personal health information, encouraged by technological trends and policies promoting patients' rights.

The following discussion will look closer into Web 2.0 and Medicine 2.0 applications and consider how these concepts may be applied to I-CAN 5.0.

2 A WEB 2.0 ENABLED I-CAN

CDS wants to empower people with disabilities to actively participate in the support process. Furthermore, CDS wants to enable the family or friends of the person with disability to participate and give feedback to the support services. They are the people who live together with the person with disability and can see changes in their health and behaviours first, often before the support service may notice changes.

However, it is important to consider that not all people with disabilities are able to use a computer, not to mention a complex online social networking tool. Only a smaller percentage of the people with disabilities who have participated in I-CAN assessments to date would have the skills to use an online social networking tool. However, certain family members or friends of the person with disabilities would be very interested to the idea of having access to I-CAN, to give feedback and updates through the year to support services or search for and connect with people that have similar disabilities or health conditions.

One of the primary limitations of I-CAN 4.2 discussed is that only support services have direct access to the system, but no persons with disabilities or other user groups. For a Web 2.0 enabled I-CAN it is necessary to give these user groups access to the system. The proposal for I-CAN 5.0 combines a social networking tool, user based site, blogs, forums and online community, as well as access to the existing or redesigned assessment system. It allows persons with disabilities, their friends/family, and the support services and health professionals to connect and interact with each other. It is a tool to empower people to take responsibility for their own health and to connect with other people with similar medical history/conditions.

This section proposes what I-CAN with Web 2.0 features would look like and hopefully be foundational for I-CAN 5.0. It is not the purpose to present a fully functional and designed application.

2.1 User Classes & Characteristics

As mentioned previously, only a small percentage of all users who have participated in I-CAN assessments to date would be able to use a social networking website. That is why there must be different roles for persons with disabilities available. While creating the profile, the support service, health professional or family member has to decide in which access category the person falls and create

the profile correspondingly. There are seven different types of users proposed for the I-CAN 5.0 social networking system (Table 1) with different roles and access rights. These access levels may be further divided into read / write access to particular domains within the profile for particular persons.

Table 1: User types roles and rights.

| Role: | Description |
|-------------------|--|
| Manager | The user Manager is the manager of a support service and has unlimited access to all functions of the social networking feature. |
| Staff | Staff users have limited access to the social networking feature. |
| Family/ Friend | This user is either a friend or a family member of one person. |
| P1 | A person with disabilities that has full access |
| P2 | A person with disabilities that has modifying access |
| P3 | A person with disabilities that has limited access |
| P4 | A person with disabilities that has no access |

2.2 The Profile

The profile is the central piece of the social networking tool. It contains all the information about the members of the site. Every profile contains a main section with a photo, name, age, and location of the person. Furthermore, the user can set his status in two ways. Either by entering a status message or by activating an emoticon that shows the mood of the user, based on the existing easy English resource used in the I-CAN assessment “How happy are you?” The user does not need to fill out all information, and can leave sections that he or she does not want to publish blank. Further, the user can mark certain sections of their profile with varying privacy, read / write access levels. For example, allowing their mother to see most parts of the profile except for the sections regarding sexuality, whilst allowing care workers to read / write most sections except long term goals and dreams.

A persons profile is based on the data that is saved in the existing needs assessment. If a person (or his/her family member) decides to participate in the social networking tool, the support service can create the profile for the person after the entry of the needs assessment information. Alternatively, iI-CAN 5.0 should allow for individual people outside of a formal support service to register and join the website. The creation of the profile could be done

automatically by I-CAN by taking information gathered by the existing assessment tool.

The profile for persons with disabilities contains the following two sections: 1) “to do” list for the person and support providers, e.g. change diet plan, monitor sleeping patterns, find more activities, etc. 2) documents prepared from support providers, or family/friends about the person, like other assessment reports, care plans, scanned documents, etc.

The support service and the person with disabilities can decide together which of the information will be visible for other users. They have the option to lock/unlock information for other users. Family member or friends of the person with disability have the opportunity to create and edit a profile as well. This profile does not contain the same information as a profile of a person with disabilities. The staff of the support service can also create and edit a profile with sections relevant to them. All access rights are modifiable, customizable and to be implemented using access tables.

As service provision moves towards individual funding arrangements, with people with disabilities employing their own staff, having an online register of disability support professionals, a profile of their skills and experience, will facilitate people with disability funding and employing support staff most suited to the person’s need and preferences.

2.3 Adding Friends

A function of the new tool is to add friends to the profile. Basically every user can become friends with any other user. So for example, support staff can add other support staff to their friends and share their experiences. Persons with disabilities can add people they meet online to their friends, or family members can add other family members and share information about their experiences with their relatives.

In a similar fashion to social networking sites such as Facebook, when a user adds another user to his friends, an email is sent to the others users e-mail address. The receiver can then accept the friend request or deny it. However, for users P4 it is not possible to add friends to their friends list. In this case, an email is sent to the person responsible, be it family or support providers and the person responsible decides if this person can become friend and see the profile.

2.4 Sending of Messages

Messages can be sent publicly (via the Comments section or forums) and privately. Users can send any other users messages, public and private (except user P3 and P4). The public messages can be entered and sent in the Comments section of the receiver profile. After the message was sent, the receiver receives an e-mail in his inbox stating that a new message was received from a user in I-CAN.

2.5 Forum

The social networking tool incorporates public and private forums. The public forums can be used by any registered user except P3 and P4 users and offers a place for discussions of general interest and posting of news and helpful information. The private forums are for discussions particular to an individual with disability, therefore are not visible for search engines as well or uninvited users.

2.6 Search Function

Users have the possibility to search for other users in the basic search (except P3 and P4). The advanced search feature enables users to search for other users based on criteria like name, age, location, goals and dreams, and diagnosis.

2.7 Status Messages

Status messages can be set as well. Users can write and change their current status anytime. 'Happiness status' and 'Health status' can be set visually by clicking on one of six available emoticons:

Very happy /Happy / A little happy/ A little unhappy / Unhappy / Very unhappy
Very healthy / Healthy / A little healthy / A little sick / Sick / Very sick

2.8 Give Feedback

A "Give Feedback" feature is located in every section of any user's profile P1 – P4. Here, all other users (except P2-P4) have the opportunity to give feedback about this particular section. For example, a family member could give feedback about the current status of his/her relative. If the family member notices changes in his relatives health, behaviour, condition, etc. he could write a feedback note in the relevant section. After sending the feedback, the responsible manager gets an e-mail with the message and the details to the person and

the section about which the feedback was sent. The manager can then reply to this feedback and/or delegate his staff to act accordingly. Staff members and users categorized P1 can send feedback messages as well. Alternatively, depending on read / write access levels, the user could directly edit the profile or assessment.

2.9 Upload Documents

Managers and P1 users can upload documents to the profile page of a P1 – P4 user as well. The manager for example can upload assessment reports, service summaries, etc to the profile, while a P1 user, a person with disability that has full access to the system, can upload scanned documents like doctor reports, or other health related documents. The advantage is that all documents are then available in one central place, easy to access for the persons with access rights to it.

3 DISCUSSION & CONCLUSIONS

One of the biggest problems with a social networking feature based around health concerns as introduced is the issue of privacy. Even though participation is on a completely unsolicited, opt-in basis, there are access and privacy issues involved in such a tool. Who can see what information? What does it mean if a person can see information that he should not see? Especially in the health sector, this is a much discussed topic. The question is, how can I-CAN 5.0 set up access and privacy rules to prevent any problems?

The access rights discussed are a preliminary solution to cope with this problem, though the full detail of assigning read / write access to particular people to particular pieces of information has not been outlined. It could be the case, for example, that a person with disability has unresolved issues with one of his family members and does not want to grant him any more access to his profile. Or the other case could be that the person with disabilities wants to share more information with people outside their immediate network. In both cases, I-CAN must have the option to grant/deny access for any user to particular sections at any time.

A special situation is given for I-CAN as well. Only a small percentage of people who have participated in the I-CAN assessment to date would have skills to use a social networking website. Why should I-CAN create a social networking tool? How commercially successful would such a system be

and is it worthwhile to proceed with the development? The benefit from such a tool is mainly for people with disability with good literacy and computer skills or family members/friends of people with disabilities. They can have access to all the information and keep up to date with changes in their relatives' situation. They can share information with other relatives in the forum and do not feel alone in their situation. The support services of course benefit from the feedback they get from the family/friends and can react quicker and provide better services.

How would family members, friends, health professionals and support services be attracted to use a system like this and keep using it over time? How attractive is it for family members to participate? How attractive is it for the staff of the support services? How much time per day can they sacrifice to look at all their e-mails and to answer them? There could be a problem of resistance from staff of support services to use the system. It is therefore necessary to point out the extra benefit of these tools.

The publicity that the launch of this site could get would be very beneficial for CDS and would attract more customers to the system. The development would need significant investment, but in the end I-CAN may be attractive for more potential customers and could be a profitable investment.

The development from Web 1.0 to Web 2.0 brought many new possibilities (e.g. Frost and Massagli, 2008), even though many elements of Web 2.0 are actually not a new phenomenon. Users can not just generate content; but social networks create completely new markets as well. Medicine 2.0 is an application of Web 2.0 and can be described as Web 2.0 technologies combined with e-health. Combined with the potential of electronic health records (Pagliari, Detmer and Singleton, 2007), Medicine 2.0 opens up many new possibilities, despite the issues such as privacy, information inaccuracy, loss of control over information, etc. it is the approach of the future in the health sector.

CDS, the creator of I-CAN, wants to benefit from Medicine 2.0, and is looking for options to extend their current system and implement Web 2.0 features. The next steps for CDS may be to scope their current customers' willingness to participate in the social networking features described.

Other redesign features of a possible fifth version of the I-CAN, such as a restructure of the assessment tool, user interface, and additional functions such as

online rostering and a user alerts system are beyond the scope of this paper.

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REFERENCES

- Arnold, S, Riches, V, Parmenter, T & Stancliffe, R (2008), 'The I-CAN: Using e- Health to get People the Support they Need', *Health Informatics Conference 2008*, Melbourne.
- Frost, JH & Massagli, MP (2008), 'Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data', *J Med Internet Res 2008*, 10(3):e15, viewed 22/12/2008, <<http://www.jmir.org/2008/3/e15/>>.
- I-CAN (2008), I-CAN Homepage, viewed 20/12/2008, <<http://www.i-can.org.au/index.php>>.
- Llewellyn, G., Riches, VC, Hindmarsh, GJ, Parmenter, TR & Chan, J (2005), 'I- CAN: Instrument to Classify Support Needs for People with Disability', Faculty of Health Sciences, The University of Sydney, Centre for Development Disability Studies & The Royal Rehabilitation Centre, Sydney.
- Luckasson, R, Coulter, DL, Polloway, EA, Reiss, S, Schalock, RL, Snell, M. E, Spitalnik, DM & Stark, JA (1992), *Mental Retardation: Definition, Classification and Systems of Support*, 9th edn, American Association on Intellectual and Developmental Disability, Washington, DC.
- Pagliari, C, Detmer, D & Singleton P (2007), 'Potential of electronic personal health records.', *BMJ 2007*, 18 August; 335(7615), pp. 330-333.