New technology in the human services

Volume 12, Nos.1 and 2

Social services in the information society: closing the gap

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Upfront

by Jackie Rafferty

Welcome to Volume 12 of New Technology in the Human Services which has departed from its usual format and brings you two major changes.

The first change is an updated size and look; as a journal dealing with software we were feeling left out in the continuing race for new versions and were wondering if we should call the new release NTHS 2000 – but decided against it.

The second and more important change is that Volume 12 is also the conference publication for HUSITA 5. HUSITA is the acronym for Human Service Information Technology Applications and represents a human network that first met in 1987. The network consists of people from social welfare agencies, further and higher education institutions as well as a range of organisations related to research and social welfare policy. As more and more countries adopt the Western mode of capitalism they also adopt the West's increasing focus on managerialism and concern for effectiveness, efficiency and evidence based practice. The HUSITA network encompasses a broad spectrum of views on these political drives but within an overarching imperative which Glastonbury identified as arising from HUSITA2 in New Jersey:

> *....out of that talk came the realisation of a developing theme which as grown steadily in importance – that IT, in the human services, or anywhere, must have an ethical framework and social integration.* (Glastonbury, 1996)

The title of the triennial conference is 'Social Services in the Information Society: Closing the Gap'. The title reflects the continuing desire of our international community to close the gap between East and West, North and South, equality and inequality, social inclusion and exclusion, the information rich and information poor. The aim of HUSITA "is to engage in the world of ICT in such a way that it contributes to, and enhances, people's well being."(Steyaert, 1999).

The papers for the conference increasingly reflect the aim of the conference with the emphasis on 'human service applications of ICT rather than a love affair with the technology itself. East and West are represented in this publication though the North - South divide is still evident with the North over-represented. The majority of the participants at the conference originate from North America and Europe with few from the Southern hemisphere. This and the previous HUSITA international conferences have all taken place within the Northern hemisphere - HUSITA 1 in the UK, HUSITA 2 in the USA, HUSITA 3 in The Netherlands and HUSITA 4 in Finland. HUSITA 5 in Budapest, Hungary aims to encourage inclusion from the Eastern European countries.

The theme of HUSITA 5 is 'closing the gap' and although there are many yawning gaps still to be closed (or even begun to be bridged) the range of papers do address many of the chasms within our increasingly global and information led society. To do justice to the excellent range of papers that were submitted for the conference we have considerably expanded the number of pages in the journal and have also published it as a double issue. Even so, we have had to omit a large number. The selection within this journal represents the diversity of research, development and practice that is taking place within human services and information communication technology and we are pleased to be able to bring this wealth of expertise to not only the conference participants but to the broader readership. This publication contains Volume 12 Nos. 1 and 2 and its companion, Nos. 3 and 4.

Usually the journal is divided into sections containing refereed academic papers, policy and practice papers and reviews. Within this volume we have broken with tradition and the papers here are presented within the four themes of the HUSITA 5 conference:-

1. Information and communication technology for specific user groups
2. Social service provision supported by technology
3. Information and communication technology in teaching and learning social welfare
4. Human services in the information society: the broader context

Although the papers are presented within the different interest areas there is, in fact, a great deal of overlap. The papers describing ICT use within social service practice and management could equally be resources for education and training; and the education and training papers provide a literature base for continuing professional development and in-service training within practice. The interest areas are therefore an artificial division but useful to help the reader navigate through the papers and conference participants to relate the journal to the conference experience.

The journal volume, numbers 1, 2, 3 and 4 starts with the micro experience of individual projects and works its way through the themes, diving deeper into the broader underlying contexts and rounded off in Volume 12 No. 4 by two excellent papers locating the micro practice within the macro information society developments. The aim of this volume is to reflect the state of the art in the use of information and communication technology within social welfare practice, management, policy, education and training. The intention is to enable the sharing of ideas, development and research and to learn from the experience of others.

Wherever possible the format of the English language follows the norms of the author's English i.e. the North American papers use the spelling of 'organization' rather than 'organisation' as is more familiar in the UK, etc. The papers written by authors who do not have English as a first language have been language edited, hopefully with a light hand, to ensure maximum access internationally. Gender neutral language has been encouraged and where first languages do not follow this concept then neutrality has been introduced.

The role of the editor in this stage of the proceedings is to present the papers so that you can find those subjects that focus on your own interest area but also to encourage you to undertake a more lateral exploration of areas which perhaps you would not ordinarily seek out but which spark your curiosity.

Information and communication technology for specific user groups

This section of the journal contains the most papers which is extremely encouraging as all of the endeavours in terms of using information and communication technology would be of little point unless the users of services benefit.

The two most significant advances within ICT since the last conference have been the growth of home and work computers linked to the world wide web and the use of the web to deliver services, information and education and, increasingly, to act as the vehicle for the growth of new communities that are not constrained by time and geographical distance. The first paper in this issue reaches straight into the heart of these developments to describe how parents of disabled children used and were impacted by an Internet based information and support project.

Nancy Shank and her colleagues in their paper *Internet based information and support: use by parents of children with disabilities* report benefits "even though the pre and post project measure were unable to show quantitative gains in empowerment or social support". In the last HUSITA publication (Glastonbury, 1996) Shank et al described the development and implementation of the Nebraska Network for Children and Families and provided early data. Here they report on the full findings of their study.

European Union projects were being reported on in 1996 at the Finnish HUSITA but over the last three years there has been a proliferation of projects within our field. HUSITA and NTHS are important dissemination vehicles for the results of this work and there are a number of papers presented here which originate from projects funded by the EU. This source of funding has provided a welcome method of taking forward research and development work but there are concerns about the lack of longer term continuity, and of the impact to the communities under study and subject to EU short-termism, with most projects having to complete complex change and development activities within short time frames.

Having recently experienced involvement in a European project across five countries I am also aware of the range of challenges when working across diverse social, organisational and linguistic cultures. Therefore it is with an insiders sense of respect that the next paper is presented. Poulson and Nicolle introduce the work of the DISCUS project (Distance Information, Support and Communication for European Carers) in their paper *DISCUS – using Internet based technology to support the practical aspects of care.* As the title suggests their primary target group to support are professional care workers, specifically those providing care within people's own homes and the paper describes the mis-match between the potential of ICT to enhance services and the low level of infrastructure available to deliver those enhancements. This situation is recognised within the early stages of DISCUS and a range of alternative scenarios developed. The project was just approaching the end of its first year at the time the paper was written..

The focus of the following paper changes to a service provider development which is included specifically because it show how improving the quality of life is not confined to partnerships within the health and social care sectors: be they state provided, through non-governmental organisations or the private sector. That is not to say this is a unique situation but a useful reminder that there is a world beyond our day to day service partners. *The Experience of an electronic newspaper service for the blind* by Paolo Graziani and Laura Burzagli discusses the results of an investigation among a sample of Italian blind users of the distribution service of the accessible electronic version of *La Stampa* (Turin's daily newspaper). Until the Design for All philosophy is integrated into all parts our lives it will be necessary for projects such as this one to close the gap caused by inequalities when general goods and services are not designed for inclusivity.

We stay within Europe moving from Italy to Germany for the next paper. Klaus Zink, Frank Leidermann and Harald Weber have developed a holistic measurement tool to assess an individual's abilities and their potential related to specific working tasks. This is described in *Computer work in sheltered employment: a systematic approach for qualification.*

Developments in Germany contrast with the paper from Russia by Alexander Shoshmin, Natalie Martynova and Anna Riabokon who present their plans in *Rehabilitation information system for people with disabilities.*

Next are two papers looking at the use of networks to support people with speech and language problems. Magnus Magnusson and Marianne Christensen describe several projects in Sweden in their paper *Virtual Networks for Language Therapy – Experiences.* They are using videoconferencing to network speech therapists and service users; and Tuula Petäkoski-Hult describes developments centred on ISAAC-Finland – the International Society for Augmentative and Alternative communication. ISAAC-Finland represents professionals, service users and their families and work has begun to use web based technology to support their community.

We stay in Finland with two papers looking at using ICT to support firstly the use of videoconferencing for professionals working over long distances and secondly the development of assistive technology for people with dementia. *Videoconferencing in psychiatry* by Mielonen and colleagues focuses on a study to look at the feasibility and costs of using videoconferencing for consultations, therapy, training and administration over long distances. Jaana Leikas, Juha Pärkkä and Petteri Jämsä in their paper *Personalised software application compensating memory disorders* describe the TASC project, partly funded by the European Union, whose aim is to develop a memory support system with an array of software modules for people with cognitive disabilities.

This section on 'information and communication technology for specific user groups' finishes with the paper by Bryan Williams and his colleagues. The authors are academics and students from the University of Dundee's Department of Social Work and the Department of Applied Computing. They report on three case study projects where computer-based interactions were developed to be used in situations where people have suffered a disabling trauma.

Social service provision supported by technology

Within the context of social service provision supported by technology there are six papers describing the use of ICT to develop, manage and evaluate social service provision. These are 'hot' topics in Western societies as a large number of countries fine tune services in order to make them more accountable, cost effective and efficient whilst ensuring services focus on the user rather than on the organisational structures.

But first Andy Bilson's paper takes us away from the leading edge ICT developments described in some of the earlier papers and places his work firmly in the difficult arena of supporting modernisation of services for children being looked after by the state in Romania in his paper on *Monitoring child care in adverse circumstance.* This paper emphasises the need to use appropriate level technology to relate Western evidence based practice to a country whose welfare services are in transition.

Whilst Gregory Stosuy and Joseph Eaglin provide a counterpoint to the first paper with the *Community Services Network (CSN): creating an integrated service delivery network.* Integrated service planning, management and delivery is the holy grail of many western social welfare agencies and this paper describes the model developed to reach that goal.

This multi-disciplinary service planning theme is picked up in the paper by Sirpa Kuusisto-Niemi with her paper describing the development work on *Seamless service chains in social welfare and healthcare.* Both papers emphasise the need to shift from services bound by organisational structures and constraints to a pattern of services predicated on the needs of the user or client regardless of the source of the service.

Developing a computer supported evaluation system in a human service organization by Peter Gabor and Jackie Sieppert from Canada suggest the most effective evaluation approaches are internally driven, rely on continuous data collection, and emphasise development rather than judgement. They have developed and implemented an evaluation system using computers which is suitable for even small agenices. Here they describe a specific development and conclude by identifying issues and considerations in designing information systems for human service organisations more generally.

Its not often that statistics is described thus 'Reading statistics is like reading poems, they are formal, concise and full of meaning'. In *Closing the gap between central and local authorities for welfare and health* Anni Hakkarainen suggests that building a network of people who are the users of the Municipal Database for Social and Health Statistics in Finland is the best way of promoting the diffusion of information and use of the database whilst reading the statistics like poetry.

This section of the journal has as its last paper a coming together of a number of the themes described above within an EU project which focuses on the 'demands to secure the greatest possible improvement in performance of public financed social and health care of the elderly through available resources' Marja Vaarama and Lic Päivi Voutilainen report on the PLANEC system which supports '*information based care for elderly people*'.

We hope you enjoy reading the papers and find much to inform your own work. New Technology in the Human Services Volume 12, Nos. 3 and 4 contain the papers relating to the themes of:

Information and communication technology in teaching and learning social welfare, and
Human services in the information society: the broader context

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Information and communication technology for specific user groups

Internet based information and support: use by parents of children with disabilities

by Nancy Shank, Debbie Laible, Virginia Murphy-Berman and Gregg Wright

Abstract

This paper describes how, over a twelve month period, parents of children with disabilities used and were impacted by an Internet-based information and support project. 89 urban and rural families were recruited, half of whom served as a comparison. Every family reported benefits from their use of the NNCF, although pre- and post-project measures were unable to show quantitative gains in empowerment or social support.

Family advocacy

In the United States, public policy governing the role of families in the care of a child with special health care needs (CSHCN) has changed dramatically, moving from a policy of professional-centered to parent-centered decision-making. *The Education of the Handicapped Act* (1986) signaled a major shift in public policy, calling for families to play a vital, if not leading role, in the decision-making process. Family-centered decision-making processes are widely considered to be empowering for parents in the health and human services system, and are increasingly recognized as the ultimate goal of professionals providing services for CSHCN.

Family challenges in advocacy

As families participate in the health and human service system on behalf of their child, they face significant stressors and barriers.

Stress

Families of CSHCN often face significant stresses that distinguish them from families whose children do not have special needs. Stress may be associated with: care-taking demands and related events (Spiegel-McGill, et al., 1990; Floyd & Gallagher, 1997); financial strains (Able-Boone, et al., 1992); marital adjustment (Suárez & Baker, 1997); sibling resentment (Petr & Barney, 1993); and lack of information, isolation and lack of support (Able-Boone, et al.).

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Informational needs

In order to care for their families and advocate for their children, parents of CSHCN must seek out and use a wide array of information, including: information about their child's disability; strategies and techniques for interacting and working with their child; applicable laws; location and availability of human services resources; financial assistance; communication methods; documentation methods; and advocacy strategies (Decker, 1991). Parents of children with special needs often lack information about available services (Petr & Barney, 1993).

Complex human services interactions

Families of children with special health care needs often require services from a fragmented service system (medical, educational, social service, and public health) that is confusing, difficult to access (Saywell, et al., 1993), with complex and conflicting eligibility requirements (Agosta & Melda, 1995; Koenning, et al., 1995). Services are often isolated geographically, financially, and culturally, and require significant expenditures of time and energy to coordinate and understand (Kelly, 1995; Petr & Barney, 1993).

The role of social support

Social support effects: outcomes during stressful life events (Albrecht & Adelman, 1984; Barrera, 1986); as well as specific behaviors such as positive parental functioning and care giving (Belsky, 1984; Ireys, et al., 1996; Thompson, et al., 1997; Meadows-Orlans, 1994); and everyday functioning (Cohen & Wills, 1985; Barnes & Duck, 1994; Braithwaite, et al., 1999; Cutrona, et al., 1986). Research shows that families of CSHCN find that other parents of children with similar disabilities to be the most desired (Able-Boone, et al., 1992), reliable, and inspirational source of support (Petr & Barney, 1993).

The Internet

The Internet started in the 1960s as a project sponsored by the United States Department of Defense to build a restricted communications system. By the 1980s, the National Science Foundation had assumed operation of the Internet and was making it available to tens of thousands of researchers and scholars. The World Wide Web was born in the early 1990s, allowing users to access text and images and to move rapidly throughout the network of networks with the click of a mouse. The commercialization of the Internet in the early 1990s both increased accessibility to consumers and promoted integration of the Internet into everyday life.

In 1993, fewer than 5 million Americans accessed the Internet (U.S. Department of Commerce, 1998). By 1995, the three largest, national Internet service providers had 10 million subscribers (Lewis, 1996 as cited by Wellman et al., 1996). By February 1998, 58 million Americans over the age of 18 were using the Internet (Louis Harris and Associates, as cited in Birdsell, et al., 1998). The World Wide Web now comprises over 320 million pages of information accessible to the casual browser (Lawrence & Giles, 1998). American users increasingly reflect the same racial and gender distribution as the general population of the United States (Birdsell et al).

Support networks, families and the Internet

Traditional social support network concepts (Thompson, 1995) are transferable to Internet-based support networks for families of CSHCN. Internet-based supportive networks enable families to: increase the size of their personal support network (network size), increase the contact with network members (social embeddedness), easily contact network members (dispersion), form stable relationships (stability), interact either with a large group or through one-to-one messages (extensivity). In addition, Internet-based support networks provide the ability to: communicate in emotionally meaningful ways (valence), give and receive support (reciprocity), identify others with similar experiences (homogeneity), expect support through the network (perceived support), and actually receive support through the network (enacted support). Two other support network features, multidimensionality and density, may be weak in Internet-based support. Multidimensionality refers to the complexity of roles assumed by members. Research suggests that users of electronic communication may, not only be perceived as unidimensional persons, but may also act in more unidimensional ways (Postmes, et al., 1998). Density in a network is the degree to which members have mutual contact. Mutual associations within an electronic support group may be weak. Weak density, however, may be seen as beneficial, particularly for those seeking different perspectives or for those transitioning to a new role (Thompson, op cit), such as parents who are learning the implications of having a child with special health needs.

What we intended to find out

This study was designed to broadly investigate the role that Internet-based information and support might play in the lives of families of children with special health care needs. Significant attention has been devoted, and time and money expended, to establish a multiplicity of websites and discussion groups, yet relatively little is known about how families use and are affected by this technology, particularly families of CSHCN, and particularly over a significant span of time. The purposes of the study were to: determine usage characteristics; determine content of messages; and analyze overall utility as information source and means of affecting policy. The project evaluation would include both qualitative and quantitative, and process and outcome data throughout a year-long period.

Methodology

Subjects: Eighty-nine families with CSHCN were recruited for participation from seven geographically-dispersed areas of the state of Nebraska, including areas that were predominantly urban and predominantly rural. Half of the families were randomly chosen to have access to the NNCF and half, who were not given access, served as a comparison group.

Design

The evaluation of the project comprised four components: usage analysis of the NNCF, content analysis of e-mail messages, pre- and post-project assessments, and participant interviews.

Network usage: This component of the evaluation was designed to assess family use of the network, as measured by number and duration of logins, messages sent and messages received.

E-mail content analysis: In order to determine the extent to which families discussed the service system with each other or with professionals, transcripts of exchanges taking place on the network were sampled during the project period. Discussion group messages (1002 messages), and person-to-person messages (a random sample of 1100 person-to-person messages of the 5581 total) were examined for references to the service system; that is, whether the messages included requests for, or provided information about, a specific policy, hospital, physician, school or program, or whether they included discussions about insurance or any other service system related issue. Two coders independently examined each message and agreed 98% of the time on whether or not a message involved the service system.

Pre- and post-project evaluations: Prior to participating in the project, participants provided demographic information and completed scales designed to assess empowerment, social support, stress, life satisfaction, and perception of service co-ordinator. A final questionnaire was sent to participants approximately 17 months after the inception of the project and 12 months following the recruitment of the final families. 70 of the 89 families (40 families with access and 30 comparison families) completed both the pre- and post-project scales. Post-test information was not available from 19 families.

Empowerment: Three subscales from a multidimensional measure of empowerment developed by Koren, DeChillo, and Friesen (1992) were used: family, service system, and community/political. Each subscale consisted of six items measured on a five-point scale (from not true at all to very true). Sample items included, "I know what to do when problems arise with my child" (family; Chronbach's alpha = .58), "I know what steps to take when I am concerned my child is receiving poor services" (service system; Chronbach's alpha = .66), and "I get in touch with my legislators when important bills or issues concerning children are pending" (community/political; Chronbach's alpha = .73). In addition to these sub-scales, the NNCF research team developed a three-item physical needs empowerment subscale. These items addressed the ability of the parent to care for the physical needs of their child (e.g. "I feel competent to take care of my child's daily physical needs"; Chronbach's alpha = .67).

Social support: The social support scale was developed by the researchers and was intended to measure tangible/instrumental, emotional, and informational support. Each subscale consisted of three items measured on a 5-point scale (from strongly disagree to strongly agree). Sample items included, "I can count on someone in my life to give me good parenting advice" (informational; Chronbach's alpha = .81), "There are people in my life who give me the moral support I need" (emotional; Chronbach's alpha = .83), and "I can count on someone to help me take care of the kids" (tangible/ instrumental; Chronbach's alpha = .82).

Stress: The Index of Clinical Stress (Abell, 1991) used in this study is a four-item scale that measures subjective stress from external demands. The items on the stress scale were rated on a 5-point scale (ranging from rarely to most of the time). Sample items included, "I feel like a want to scream" and "I feel like I am stretched to the breaking point"; (Chronbach's alpha = .84).

Life satisfaction: The life satisfaction scale was a one-item scale developed by the researchers. The scale presented the participant with a picture of a ladder with seven rungs. The top rung of the ladder represented the best possible life for the respondent and the lowest rung represented the worst possible life for the respondent. Respondents were instructed to indicate which of the seven rungs represented how they currently felt about the status of their life.

Perception of service co-ordinator scale: The perception of service co-ordinator scale was modified by the NNCF research team from a shortened version of Brass Tacks (McWilliam & McWilliam, 1993), and contained eleven items measured on a 5-point scale (from never to always). Sample items included, "My services co-ordinator addresses my concerns on the very first contact" and "My services co-ordinator listens to my ideas about ways to teach my child or how I think my child learns best" (Chronbach's alpha = .90).

Qualitative interviews: Semi-structured telephone interviews were conducted with parents and service co-ordinators. 32 network parents (of the 40) were interviewed. The interviews were designed to assess patterns, benefits, and barriers of use, impact of the network on the lives of families, expectancies and surprises in using the network, and suggestions for improving the network. The interviews were conducted after the post-test (i.e. the final questionnaires) were received.

Content and structure of the Internet resource

Hardware, training and support: NNCF families received: computer terminals, previously used in U.S. West's Community Link project (Maciuszko, 1990); one-to-one training; toll-free Internet access; access to the NNCF World Wide Web site; e-mail accounts; subscription to NNCF electronic discussion groups; and on-going assistance through a toll-free help line and e-mail.

Discussion groups: Families were subscribed to the discussion groups for communicating with other families, services co-ordinators, state officials and researchers.

Information content: A website was designed to allow participants to access a wide variety of information relevant to issues of raising CSHCN. Information included links to governmental sources (e.g. Social Security Administration, Indian Health Services), non-profit advocacy organizations, state agencies, project information, health and disability resources, search engines and other relevant links. Other specialized content included a database of 8000 health and human resources and a program enabling parents to ask a licensed pharmacist about drugs and drug interactions.

Procedure: 16 services co-ordinators from seven geographically-dispersed areas of the state were selected to participate in the project. Service co-ordinators were asked to invite all eligible families in their caseload to participate in the project. Families were excluded from recruitment only if the service co-ordinator judged that even presenting the option to participate would be harmful or stressful to the family. Half of the willing families were randomly chosen to have access to the NNCF and half served as a comparison group. Eighty-nine families were recruited for participation in the project. Each NNCF family or user was assigned a unique identification number to employ when logging on to the NNCF.

Results

Network usage: The majority of NNCF families used the network. Only six of the network families failed to use the network at all or used the network for less than one month.

Logins: Overall, NNCF families spent a total of 2478.7 hours on the network and logged onto the system a total of 7396 times. Families spent an average of 5.16 hours per month on the network (range 0-114.5 hours) and logged on an average of 15.4 times a month (range 0-222 logins). Figure 1 shows the total minutes families were logged onto the NNCF by month over the year.

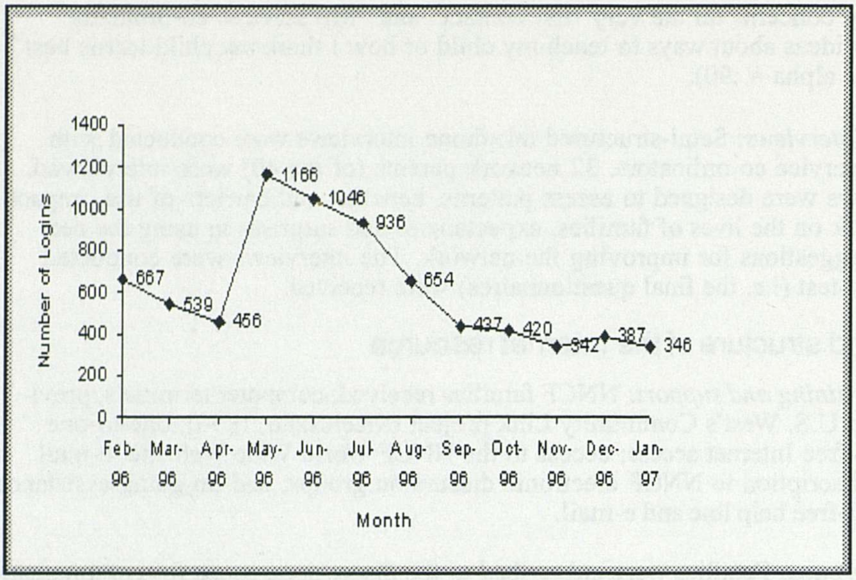

Figure 1 Total family logins to the NNCF by month

E-mail messages to discussion groups: Families sent a total of 1002 messages to the discussion groups. An average of 2.1 messages a month were sent by families to the discussion groups; however, this ranged from 0 to 127 messages. Network families sent a total of 5581 messages to each other (i.e. to other network families or service co-ordinators) across the 12 months of the study. Families sent an average of 11.62 messages a month to other network families (but this ranged from 0 to 1082 messages). Network families also sent a considerable number of messages (a total of 1144 messages) to others outside of the network. Families sent an average of 2.4 messages a month to individuals outside of the network. Figure 2 shows the total messages families sent to the NNCF discussion groups over the year study.

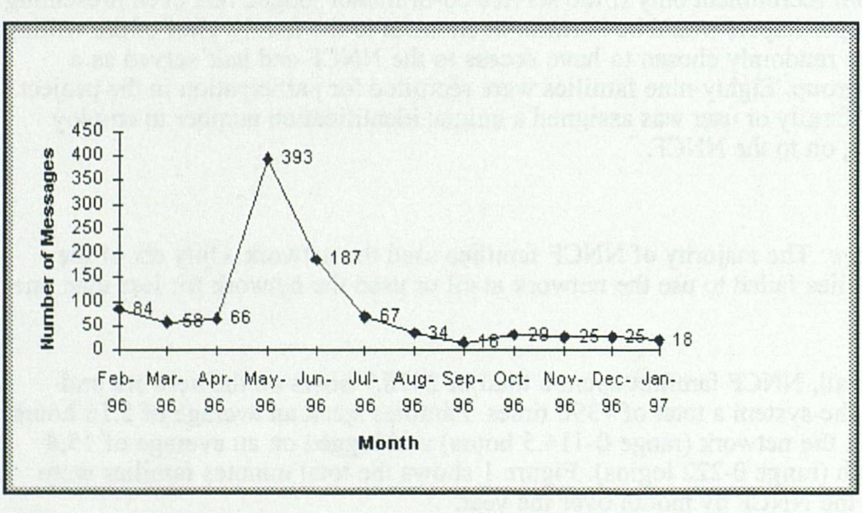

Figure 2 Messages sent to NNCF discussion groups

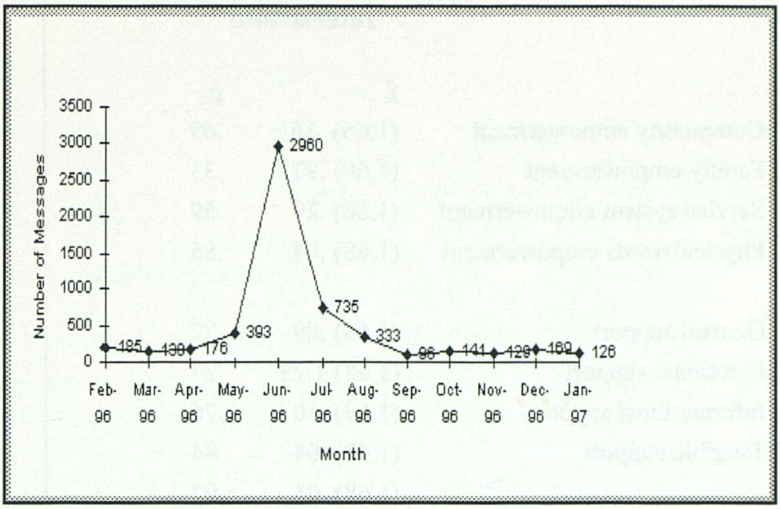

Figure 3 No. of person-to-person messages families sent by families to other NNCF participants

Patterns of use over duration of study

Initially, families used the network with much fervor; however, across time the network usage of families leveled off to more steady but lower (and perhaps more reasonable) rate. This pattern was described by one participant in the interviews, who explained their families' initial reaction to the system:

> *I would say that when we first got it, we were addicts. We were like, what is this? What does it do? . . . Now we're probably down to connecting to it two or three times a week, instead of two or three times a day, which is what we did at the beginning. I think now, we probably use it for keeping track of what's happening with meetings, services, and things around the area. In the beginning, it was more of an outreach on the personal level with different families, and finding out about who and what and all of that.*

Pattern of network use

The amount of time and numbers of messages send by an individual varied widely, as shown in the ranges above. These highly variable patterns of usage are similar to those found by other researchers (Dunham et al., 1998). Usage patterns were examined in relation to demographic factors to determine what, if anything, was related to the manner in which the system was used. Chi-Square analyses revealed that the pattern of use was unrelated to:

Race ($\underline{x}^2 = 7.14$, $\underline{p}$=.62),
Education level ($\underline{x}^2 = 17.1$, $\underline{p}$=.32),
Income level ($\underline{x}^2 = 19.5$, $\underline{p}$=.19),
Previous computer experience ($\underline{x}^2 = 2.00$, $\underline{p}$=.58) or,
Being from an urban or rural area ($\underline{x}^2 = 5.76$, $\underline{p}$=.12).

These data suggest that factors, other than these demographic factors, determined the pattern of and extent of network usage by families. Dunham et al. were unable, similarly, to find a correlation between use and socioeconomic resources, age, previous experience with computer or other factors. They were, however, able to find predictors of usage in measures of social isolation.

Scales		Interactions	
Empowerment		f.	p.
	Community empowerment	(1,66) .16	.69
	Family empowerment	(1,68) .97	.33
	Service system empowerment	(1,68) .29	.59
	Physical needs empowerment	(1,68) .04	.85
Support			
	General support	(1,68) .09	.77
	Emotional support	(1,68) 1.23	.27
	Informational support	(1,68) .10	.76
	Tangible support	(1,68) .04	.84
Stress		(1,68) .01	.92
Life satisfaction		(1,66) .46	.52
Perception of services co-ordinator		(1,68) .16	.69

(NB: Values enclosed in parentheses represent degrees of freedom.)

Table 1 Pre-to-post project analyses of interaction

E-mail content analysis

Discussion of service system. The analysis of the e-mail messages suggested that network families discussed the service system in both discussion group and personal messages. 26% of the NNCF discussion group messages and 18% of the family discussion group messages involved some discussion of the service system. Eight percent of the family-to-family messages involved the service system.

Selected conversational threads. Families not only discussed the service system in discussion groups, but their daily struggles. For example, families shared difficult family experiences, child milestones, local advocacy efforts and advice, and information sharing about everyday issues such as insurance and funding for diapers.

Pre and post-project evaluations

Descriptive data and assumptions. We began the project with the assumption that both our project and network families would feel somewhat isolated, unempowered, stressed and perhaps also low in life-satisfaction. The descriptive data, however, from the pre-project assessments suggests otherwise. Except for community empowerment, the mean pre-test scores on empowerment were high (ranging from 4.28 to 4.44 on a 5-point scale). Likewise, mean scores on the pre-project support scales were also high (ranging from 5.53-6.01 on a 7-point scale), as were pre-project mean scores on the perception of service co-ordinator scale (4.48 on a 5-point scale). The only mean pre-test scores that were moderate were those on the life-satisfaction scale (4.41 on a scale of 1-7) and those on the stress scale (2.50 on a 5-point scale). Thus, overall the descriptive data suggests that although project families reported moderate amounts of stress and life-satisfaction, project families felt relatively supported and empowered, and in general had a positive perception of their service co-ordinator before the NNCF project began.

Pre-to-post project analyses

A series of repeated-measures, ANOVA's, were used to look for differences in the pre and post-project scores of network and non-network (i.e. comparison) families on empowerment, support, stress, and life-satisfaction. For all variables, the analysis showed no significance between groups or across-time differences. Table 1 displays results for interaction between group (project vs. comparison) and assessment time (pre to post-project).

Qualitative interviews

Evaluation of resources and communication

Several questions on the qualitative interview were aimed at understanding how network families assessed both the communication and resources on the network. These questions focused on the benefits of using the system, aspects of the system that were particularly helpful, the amount of support families felt in using the network, and if the network increased their access to service co-ordinators. The family responses suggested that most families viewed both the communication and resources on the network favorably.

Every family that was interviewed reported some benefit to using the network. The most commonly cited benefit by families centered on issues of support. 48% of the network families interviewed reported that the most important benefit of the project was making connections with other families who had children with special needs. One parent reported that for her the benefit was "just knowing that you have somebody else to talk to, even though their kid doesn't have the exact same thing; some situations are similar." Similarly, another parent reported that for her the benefit of network use was "just knowing that you are not the only one out there struggling every day." The second most commonly reported benefit of using the network (reported by 32% of the families) involved the informational resources families discovered on the network or advice they received from other families. One parent reported:

> *I really feel that it filled a void in our lives, because it made us much more aware of what was out there. There are a lot of things that I didn't even have a clue about, and now, if I wonder about it, I just put it up there and say who knows about this? And, I think that even in the school district, we get good services and everything, but there's a lot of stuff you just don't know about. [The NNCF] brings a lot of information right where you need it, real quick.*

56% of the parents reported that they felt supported and that they made connections through their use of the network. "It gave me a social place to go without having to make an appointment, get a babysitter, arrange to have kids picked up and dropped off," reported one mother. Another network parent reported that she "talked with a lot of families, but there were two specifically that I really connected with. And I felt like if I had any questions, I could ask them." Families who reported that their use of the network did not increase their support, often reported that they either did not use the system (16%) or that they already felt supported (8%).

When asked which aspect of the network was the most helpful, 36% of the families reported that the WWW site was the aspect of the network that was particularly helpful. Discussion groups and e-mail were the second most frequently cited helpful aspect of the system (28%).

The vast majority (64%) felt that the project increased their access to and communication with service co-ordinators and other professionals. Those who did not feel that the project enhanced their communication with service co-ordinators and provided a reason, reported that they either did not try to contact either service co-ordinators or professionals through e-mail (16%) or that they already felt well-connected with their service co-ordinator (12%).

Impact of the network on the lives of families

Several questions on the qualitative interview were designed to understand the impact of the network on families. These questions focused on how the network impacted the lives of families, on whether or not the network changed relationships, on how their life was different as a result of the network, and on the long-term effects of the network on the family. The responses that network parents gave to these questions suggest that the network had a greater impact than the quantitative measures would suggest.

When asked how the network impacted their lives, 80% of the families reported that their use of the network had a positive impact on their lives and these families reported numerous ways in which the network affected their lives. The majority of these families suggested that it was both the access to information and connections that they made with other families that had the greatest impact on their lives. One network parent reported that the network impacted her favorably because "I have been able to access the information that I needed, anytime I needed it." Another parent suggested the network "made me more comfortable with knowing that I am not alone and that if I need to talk with somebody on the same level where I am, then they are out there." Other families reported that the network impacted their lives by teaching them to stand up for their child's needs, by opening their eyes to technology and a new way to communicate, and by helping them to learn to communicate with others.

Nearly half of the interviewed families (47%) reported that their experiences with the network changed their relationship with their child. These families gave a variety of ways in which the project changed this relationship, including being more comfortable in meeting the child's needs, understanding the child's needs better, trying new activities (learned through the network) with the child, and finding new ways of dealing with the child's difficulties.

30% of the families felt the network positively impacted their relationship with their spouse.

20% reported that it positively changed their relationship with other family members.

9% reported that it positively changed their relationship with their friends, and

20% felt that the network positively changed their relationship with their service co-ordinator.

90% of the network families thought that their life was different as a result of their experiences with the network.

Of these families, the majority (i.e. 66%) felt that their lives were different because they were more knowledgeable or because they were more aware of the struggles of other families of CSHCN. One parent reported that "I just feel a lot more knowledgeable about what my son has gone through and what we can do for him, places that can help him - more than I did before." Another reported that "I feel more relaxed talking with people, because I know that there are a lot more people out there than I had originally thought with the problem that I face every day." Two-thirds of participants in the network also felt that the network had long-term effects on their family. These families said the knowledge that they acquired from the network and that the connections that they made would have lasting effects on their families. One parent responded that the project "opened up a lot more programs than I knew about that are always available for [my child] and ways to help keep her growing and developing as much as we can."

Discussion

The NNCF

Positive impacts: Families reported that the NNCF resources and communication were beneficial and that the NNCF positively impacted their lives. Interviews, selected conversational threads, and stories told to project staff by NNCF participants suggested that families found relevant information, connected with similar families, and had meaningful conversations through the NNCF. In addition, the majority of network families felt that the NNCF positively impacted their lives and that the connections they made and information they discovered as a result of the NNCF would have long term benefits on their families.

Usage not related to demographic factors: Family use of the NNCF was unrelated to demographic factors, including race, education level, income level, urban or rural residence, or prior computer experience. This finding suggests that families are likely to use Internet-based resources, if provided access.

Discrepancies in data: Despite the mostly positive qualitative data, we were unable to show quantitative gains in empowerment, support, stress, life-satisfaction, or perceptions of service co-ordinator as a result of NNCF involvement. It is unclear as to why a discrepancy exists between the quantitative and qualitative data. It may be attributable to a ceiling effect with the quantitative measures, or that the scales were too broad in measurement (e.g. an index of parental stress may have been more appropriate than the more general stress scale). Other researchers (Brennan, et al., 1995) have reported similar incongruencies between usage and reported affect, and quantitative changes.

The Internet as a tool

Information and support: The Internet is a rich source for electronic support, and health and disability-related information (Fullmer & Majumder, 1991; Brown, 1997). However, finding credible, relevant information may be challenging. Even the best search engines index no more than 40 percent of all the pages (Lawrence & Giles, 1998) and more than half of health and medical information websites may be providing biased or inaccurate information (Brown op.cit).

Unequal access: As the Internet becomes an increasingly integral part of our culture, and as more and more information is communicated through the Internet, there exist serious concerns about a growing divide between the 'information haves' and the 'information have nots'. Despite increasingly low-cost hardware and greater access to Internet connectivity, disparities persist. In the United States, rural Internet access continues to trail suburban and metropolitan, and persons with a lower educational attainment (high school or less) and those who are older (65 years and older) continue to be under represented (Birdsell, et al., 1998). And the gap of connectivity is widening for lower income groups, female-headed households, central city, and blacks and Hispanics (U.S. Department of Commerce, 1997). Persons with disabilities, particularly visual disabilities, also continue to face barriers in accessing information, such as with screen readers which may be unable to translate frames, fancy graphics, tables and columns.

Civic participation: As the Internet is a means of finding information and support and empowering families, it also provides a tool for supporting greater citizen participation in the political process (Servon & Horrigan, 1997). According to Katz (1997), "the more connected we are, the more democratic we are, the more likely we are to vote, the more we know about our political system, and the more faith we are likely to have in it". The majority of Congressional offices predict that the Internet plays an increasingly influential role in constituent communication (Bonner & Associates, and The Center for Congressional and Presidential Studies, 1998). In business settings, researchers have found that e-mail is a preferred communication method when sending messages 'up the hierarchy' (Sproull & Kiesler, 1986). No studies could be found that have investigated the transferability of this tendency to the political organizational process. Research investigating citizen predisposition to using e-mail for communicating with appointed and elected officials 'up the political hierarchy' is an intriguing direction for future research.

The Internet is a tool which may enable families to find information and support and to enable them to more actively participate in advocating for public policy change. Government and human service organizations should investigate how the Internet may supplement traditional forms of communication, case management, support and information dissemination. However, it is important that continued research be conducted to understand both the benefits of the new technology as well as understanding what our culture loses as the technology is adopted.

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DISCUS - Using Internet based technology to support the practical aspects of care

by D.F. Poulson and C.A. Nicolle

Abstract

The following paper provides an introduction to the work of the EU funded DISCUS (Distance Information, Support and Communication for European Carers) project. The paper summarises the work carried out in the project since it began in July 1998 and provides an overview of the progress made in defining the needs of professional care workers for such support. The way in which the DISCUS system will satisfy these requirements is also discussed along with the work activities planned for the rest of the project.

Introduction

The primary objective of the DISCUS project is to develop Internet based resources which support professional care workers in the practical aspects of their care work, and which can be applied in the education, training and support of carers in remote locations. Professional care worker in this context is defined as: workers providing care for non-family members and receiving financial remuneration for their services.

The services being developed in the DISCUS project include providing information and advice on care provision as well as electronic mail services. DISCUS will allow care workers to exchange ideas and benefit from the knowledge base of other professional care workers and also provide opportunities to gain remote access to information and training in good care practice. Key phases of the project include the development and evaluation of a generic support system, which can be applied in a range of care cultures, and the practical demonstration of this system implemented in Italy and Greece.

The rationale for the EU DISCUS project (DE 4202) stems from the observation that cost-effective professional social care services are becoming increasingly important due to changing demographics and increased expectations. People are living longer and expecting higher levels of care. Increasingly this also means providing care which is matched to the needs of clients, rather than on the basis of convenience for care management. One outcome of this in many countries has been a shift in emphasis away from the institutional care

http://www.lboro.ac.uk/
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of elderly and disabled people towards more care in the community (Davies 1995, Steyaert et al 1996). There is a trend towards providing more care to clients in their own homes rather than in care institutions, and there is consequently an increased demand for well trained and informed staff to provide home care. Clients have a need for basic support with daily living activities, including personal hygiene, washing and cleaning, and feeding, but in addition care workers may also be requested to carry out a range of additional activities, e.g. home administration and shopping. Such professional carer workers are often relatively poorly paid, have low levels of formal education, and may receive limited training to carry out their work. The majority of professional care workers are female and commonly work alone in individuals clients' homes. Often they have limited access to training and support from other care workers. Telematics could therefore provide an effective way of supporting such workers. There is the opportunity for telematics to increase the efficiency and quality of care by making shared knowledge, skills and experience more accessible to such care providers. This is particularly relevant in rural communities, where care workers may have little or no opportunities to share knowledge and experiences with their peers. Support for non professional family carers is not explicitly considered within the DISCUS project. These issues are being addressed in another EC funded project called ACTION which is developing home based information and communication services accessed by a television based information system (Tetley et al 1997).

Methodology

DISCUS has developed its user requirements and functional specification by following a user-centred design methodology. This has involved interviewing a sample of care workers and their managers in Italy, Greece, Netherlands and the UK, in order to better understand the likely needs for information and support of hands-on care workers. A common interview structure and questionnaire was agreed within the consortium, and then translated for use in the different countries represented in the consortium. This information has been analysed in order to identify common themes, with the objective of defining the requirement for a generic information and support system, which could then be tailored to local needs. Further analysis within the project consortium led to the development of a generic structure for a care information system which will also be evaluated with a sample of potential end users. This will lead to a refinement of the functional specification for the generic DISCUS system, which will be evaluated early in the year 2000.

A total of 119 care workers were interviewed during a three month period in late 1998. Interviews took place in Italy, Greece, UK and the Netherlands. The majority of these were hands-on care workers, providing care to individuals in their own homes. Emphasis was also placed on interviewing those with responsibility for the practical aspects of care, and did not explicitly include workers providing specialist medical care. However, it was noted that in some countries, aspects of health care were provided by non-medical professionals in the persons' own homes and that basic healthcare would therefore be an appropriate topic to include in some countries.

Summary of findings

Considerable overlaps were found in the skills and attributes of care workers consulted in the DISCUS data capture activities, and these have implications for the design of the DISCUS system. Care workers were characterised by not having high levels of education and experience of using computers was generally low. The sector was also largely characterised by a dominance of female employees, who were often working on a part-time basis. In most countries a clear distinction was also made between the medical aspects of care which required more specialist staff to provide support, and more basic care related to cleaning the home, personal hygiene and feeding. The latter was usually provided by home care workers, with doctors and nurses responsible for medical aspects of care. Poor access to information was also a common theme within the data capture activities, and in some cases low levels of training for professional carers was reported.

Some variability was identified in the perceived need for improved communication with work colleagues and this in part appeared to be related to the availability and reliability of existing telecommunications infrastructures. Mobile phones were identified as a technology which would improve the communication links between care workers operating in the community and their supervisors, but in all cases access to this technology was limited either due to basic cost or conflict with existing work practices. Care workers operating in clients' own homes did appear to require improved communication structures, though it was unclear whether e-mail or other text based media would be the most effective form for this to take. Communication between direct peers appeared to be less essential, but could be desirable from the perspective of a wider support infrastructure to allow care workers to discuss difficult cases and to share experiences. Improved communication with other associated service providers was a clearer requirement, however, as it was noted that there was often a lack of co-ordination and communication between different organisations providing services to the home. Often medical and social care services were poorly co-ordinated, and improvements could be made in this area.

Data capture activities also explored the perceived need for support from external experts, and in general this was also seen to be desirable. However, what is less clear is the extent to which such a service would be used by care workers directly, as line management was reported as being the preferred mechanism for providing expert support, and in dealing with difficult care cases.

Analysis of the sector also revealed that there was an increasing number of private organisations operating to provide care services, with the state often acting as the procurer or funding body rather than the service provider. Many small organisations existed, but it was also common for there to be a small number of larger private agencies operating in this sector and providing a wide range of services. In addition to the professional organisations, volunteers and organised charities also had a significant role to play in providing services to elderly and disabled people in many countries. Whilst outside the scope of the DISCUS project, the role of the family carer in providing support should not be underestimated.

Care can be provided in a variety of settings, ranging from the individual's own home through to specialist residential care units. In all countries within the DISCUS consortium there was a trend to provide more care in the individual's own home, and it was also identified that these workers would have a greater need for support. Care workers in residential care homes and day centres usually had access to other staff who could share experiences with them, provide emotional support, and provide practical advice when needed. Conversely, care workers working in client's own homes were often isolated from their peers (apart from their immediate management) and support provided was often of a limited nature. It was therefore identified that support for care workers in client's own homes should be a primary focus for the DISCUS project's activities.

Information/ training needs

Care workers interviewed requested information on a variety of topics that could be provided by a computerised information resource. These included:

- Advice on basic care, cleaning, personal hygiene, feeding
- Information on illnesses, disease, disability, ageing, and diversity of symptoms
- Medication and side effects

- Individual rights, dignity and self-respect
- Cultural awareness: working with ethnic groups
- Encouragement to think/take initiatives
- Legislation, legal responsibilities, eligibility criteria (and how these can change)
- Directories of other agencies and services
- Health and safety
- Communication skills and how to deal with difficult clients
- Use of care equipment
- Sources of expert knowledge
- Training available
- Activities and places for elderly and disabled people to visit

Care workers also expressed concern that they lacked information on specific clients. These included:

- background of the client (family, friends, relationships, medication, previous employment, hobbies). This was seen to be useful to make communication with clients easier.
- the client's physical and mental abilities when giving them care in the home. This was a particular concern when dealing with clients with cognitive and emotional problems who might also be aggressive.

The quality and degree of training in this sector varied considerably, and a common problem was a lack of resources to train staff effectively. Distance learning materials were identified as one possible solution to this, but concerns were raised that the practical nature of the work made hands-on training critical, and that technology would be a poor substitute for practical training courses.

Communication/support needs

Communication with other care workers was not generally seen as a problem area, but care workers providing services in clients' homes reported some isolation from their peers, with work communication being largely limited to care managers. More significant difficulties centred around the inability of care workers to communicate easily with clients when disability made this hard, e.g. when clients were cognitively impaired or had suffered strokes. Care workers in the home also expressed a desire to have more support in their work, as often it was difficult for staff to contact line managers easily. Mobile phones were generally not being used in their work, but were a common wish for the future. In addition to better communication between carers and their own organisations, a need for improved links to other care professionals was also noted. Increasingly more sophisticated medical care was being provided in clients' own homes, and so improved links to medical and other care professionals would be appreciated.

Attitudes/use of technology

Care workers were largely characterised as having a low experience and use of technology to support work, and where computers were used they were being used by management for word processing and task scheduling rather being an integrated aspect of care workers' activities. Care workers had limited access to computers and in none of the organisations consulted was there access to WWW or email facilities for care workers. Awareness and experience in using computers was severely limited, and attitudes to using technology were generally mixed.

Discussion of findings

The investigations carried out in the DISCUS project have revealed that professional care workers perceive that there is some potential for the use of Internet based technology in supporting care provision, but that there is a lack of current experience in using technology to support hands-on care work. Where it is used, computer based technology is primarily used by care managers, and the take up of such technology is primarily limited to scheduling of work activities and word processing. Care is perceived as primarily human centred work, and many of those attracted to the care sector are likely to have little experience and motivation to use computers. In addition, access to computer technology is perceived to be problematic for such groups, as hands-on care is often provided in remote locations where access to computers would be difficult, e.g. a client's own home. In the absence of working demonstrations, care providers also found it difficult to make detailed comments regarding the possible use of technology. For this reason it was decided to adopt a more prototyping approach to development in the project, where demonstration systems would be developed and then evaluated with potential users. This in turn would lead to a refinement of the product specification and redevelopment of the DISCUS system.

Access to computer technology by care workers will remain a potential problem in the short term, and alternative scenarios to operating DISCUS therefore need to be explored. A number of options are seen to be feasible alternatives to having computer terminals located in the homes of clients. One scenario is that access to DISCUS is solely through terminals located in central locations such as the offices of service providers, and that care workers visit their offices to gain access to the system. In the longer term such access is seen to be less of an issue, however, as the use of the internet technology spreads, and access through mobile phones and through television based services becomes established.

Attitudes to the use of technology in this sector remain mixed, however, and this is perceived to be a barrier to exploitation. Care is needed to ensure that the technology developed matches closely the skills of its potential users, and for this reason simple and easy to use systems are paramount. The education levels of hands-on care workers in this sector are generally low, and experience of using technology limited. This means that considerable effort will be needed both in the choice of suitable information to be put into the DISCUS system, how it is presented, and how easy it is to access the services provided.

Care workers have been identified as the primary target for DISCUS services, due to low levels of education and training, and the anticipated growth of this sector. Supporting care in rural and remote locations will increasingly become important due to changing demographics and the migration of the young to urban areas. Cost of technology and services will also be a critical factor in this sector. Implications for the design of DISCUS include:

- DISCUS needs to use existing technology where possible. This means that it must be possible to mount on existing personal computer platforms, and using existing telecommunications infrastructures.

- Ideally access to DISCUS should be possible at site of service provision, i.e. in the clients' own homes.

- Where possible DISCUS should provide a stand-alone solution. The DISCUS package will need to be self-contained and not be reliant on other technologies. A plug and play philosophy should be adopted where users are led through the setting up and use of the DISCUS service in easy step-by-step stages.

- Where feasible, connection time to telecommunication services should be minimised to reduce service cost.

- DISCUS needs to be simple to use, and not require a high level of training. A high priority will need to be given to simple and easy-to-use interfaces.

- Use of the DISCUS system should involve the minimum number of key presses on the part of users, and should not require good typing skills or the need for exact spelling.

- Training materials in the use of DISCUS will need to be developed as part of the DISCUS package, and this will also need to be integrated with good help and support facilities.

- Services should be accessible to a wide range of the population following the principles of accessible design. This will allow the system to be used by more elderly care workers, and also allow the easy extension of the systems usage to family carers if required. Large text and easy-to-read fonts are examples of these principles.

Future plans

The DISCUS project has been running since July 1998, and in that time has made considerable progress in defining the needs of a generic information service for care workers. The project is now moving into a prototyping phase where a working system will be developed in English, and then evaluated with a sample of care professionals. Feedback from these activities will be used to refine the specification for the generic system, which will then act as a template for developing specific demonstrations of working systems on the island of Samos in Greece and in Ancona, Italy. These trials will be used to assess the value of the DISCUS concept in the care sector and in addition will demonstrate the feasibility of developing a generic specification for information, training and support systems in the European context. Further information about the DISCUS project can be found on the project WWW site based at: http://www.lboro.ac.uk/research/husat/discus-web

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Experience of an electronic newspaper service for the blind

by Paolo Graziani and Laura Burzagli

Abstract

This paper discusses the results of an investigation among a sample of Italian blind users of the distribution service of the accessible electronic version of the Turin's daily newspaper *La Stampa*, realized within a project supported by the Ministry of University and Scientific and Technological Research.

Introduction

Access to daily newspapers represents a key aspect of the general problem of access to information by visually impaired people. Today, in every country, many daily newspapers provide their WWW site available via Internet, giving a general presentation of the contents of their printed version.

In principle, the electronic version of any text, including newspapers, represents the best presentation form of information for a blind reader, since it can be easily converted into an alternative form, such as an oral presentation, via speech synthesis, or a tactile presentation by means of a printed or a refreshable Braille output.

Unfortunately, from a practical point of view, the electronic information is not completely accessible by visually impaired people because of the multi-media environment in which it is presented, with redundant and often useless graphical components creating barriers for a person who needs information suitable for a textual translation.

Incidentally, it can be observed that, in the case of blind users, problems related to the access of remote electronic information are not limited to the contents of the document, but also derive from the use of graphics in every step of the chain in which the access is organized. Firstly the user interface of the operating system, secondly the user interface of the navigation software (browser) and finally the contents of the electronic document. Usually, the use of a 'screen reader' allows the blind user to have access to user interfaces of both the operating system, such as MS Windows, and the browser. Other solutions for these first two steps of the chain can be represented by special browsers, especially designed for blind people, which ensure the access to multi-media documents in a transparent way compared to the environment of the operating system.

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Once we have overcome the first two possible barriers, we can focus on the specific problem of accessibility of multi-media documents. This subject is studied today by several research organizations and adequate guidelines are available to ensure the compatibility of the use of graphics and pictures with the accessibility by blind people as well as of the use of sound and speech for the accessibility of deaf users. Nevertheless, these rules are neglected by most developers of WWW sites, including those dedicated to daily newspapers, so that blind readers find a lot of problems in accessing these sites.

Taking into account this scenario, within the framework of a National Project of Telemedicine, supported by the Italian Ministry of University and Scientific and Technological Research, a dedicated site has been developed, in which a completely accessible electronic daily newspaper has been made available for everybody, including blind and low vision readers. This was possible thanks to the cooperation of the publisher of one of the most popular Italian newspapers, *La Stampa*. They agreed to send us material every night (the articles written in a proprietary code and format) identical to that sent to the company producing the online version of their newspaper, http://www.lastampa.it

Design criteria

Design criteria for an information distribution service is very important in order to ensure the accessibility of its contents and its user friendliness for all.

Such criteria are based on two fundamental points. First, knowledge of disability is required in order to have a clear idea of the profile of the typical user. This allows the designer to avoid a product that does not match the real needs of users. This is the risk we run every time we imagine a model of the user which is too far from reality.

The second basic element is the knowledge of the possibilities offered by the most advanced technologies, from both positive and negative points of view. Note that both these opposite aspects are always present in any new technological development concerning the impact on problems of disability, especially in the field of telematics. In similar cases, such as that of HTML language, these two aspects have been taken into consideration at a standard definition level, with the result that there are a number of language elements, rules and guidelines especially designed to ensure the accessibility of documents. In many other cases, we are not able to prevent the negative aspects of a new development and we then have to look for a solution of the problem of new barriers created by those new technologies. In the case of our service, we have been considering aspects of accessibility since the first design stage.

The first objective was the development of a service able to reach an as broad a user population as possible, taking into particular consideration the problems of blind people. At the same time, we wished to improve the access quality compared to the current level of other services for blind users. We also wanted to ensure good access with any browser, regardless of its release or performance. Often blind users are provided with adapted programs conceived for them as easy to be used but often offering performances that are not comparable with the latest releases of the most common graphical browsers.

Incidentally, it can be observed that this criteria is the reverse of the one usually followed by most Web authors who tend to use the most advanced technologies. This then forces people to continuously update their browsers, in order to be provided with suitable features and plug-in modules in order to be able to interpret otherwise inaccessible documents. This situation is described by messages such as “Best viewed with ....”, which represents the opposite of the accessibility principle. To ensure complete accessibility of a document it is necessary to know how that document is viewed by the different browsers, including the ones which are not provided with multi-media facilities or special plug-in elements.

The best access to Web sites is based on a perfect match between server and client, i.e. between programs running on the remote systems and programs running on the local machines, throughout the HTTP protocol. This means that every time the application or the document made available by the server presents some features which do not match with the interpretation capability of the software running on the client, that is the browser, an accessibility problem occurs for the user. Therefore, a service organized in such a way as to ensure compatibility with the lower performing browser results in a service accessible to everybody but cannot use some of the advanced technologies or multi-media components. In our case, this does not represent a limitation since our daily newspaper consists of a set of articles, without images, so that we were able to organize the service with no graphics, pictures, animations, sounds, etc. The only graphics are the logo of our institute and the one of *Bobby*[1] validator, a tool made available by CAST (Centre for Applied Special Technology) for automatic evaluation of accessibility at the language level. (http:///www.cast.org/bobby)

Adopted solutions

After finding the best solution by adopting a purely textual presentation for the content, we devoted our attention to accessibility problems on other levels, such as document structure, navigation facilities and connection costs. In fact, accessibility is not just an issue of being able to read everything but presents challenges in order for the service to be effective.

A good document structure improves the accessibility in terms of easy and quick navigation. In the case of our newspaper, we adopted a double tree structure to organize the hundreds of articles. The first tree structure is based on a classification of articles according to a list of subjects, i.e. on a logical criterion, whilst the second is based on the pages of the printed version, i.e. on a spatial criterion. These two navigation structures allow the blind reader to get an idea of the general contents of the newspaper and then easily select any article by means of the different lists of titles related to the different subjects or pages, according to the his/her choice. Moreover, a search engine allows the reader to find any word or combination of words in the whole newspaper, so that s/he can use a personal access key to quickly reach any article dealing with a topic related to that term.

By following one of these two tree structures, once a certain article has been selected by means of its title, a separate page presents, on request, other pieces of information related to that article, such as its 'headline' and 'subtitle', the name of the author, the length of the article and its position inside the page of the printed version. This allows the reader to better understand if s/he is really interested in reading the body of the article.

Finally, three different reading possibilities are made available. The first one is the sequential reading of the whole article, that is the normal reading of a text. The second and third are two different forms of 'quick reading', just to summarise what the writer says in it, avoiding having to read the complete text. These forms respectively present just the beginning of each paragraph or sentence, so that the blind reader is in a similar condition to a sighted reader just glancing at an article. These quick reading facilities have been designed to overcome the onerous limitation of a sequential reading, such as the typical one when a text is converted by a speech synthesizer. This is one of the main differences between oral and visual reading.

These solutions of effective navigation and the quick selection and reading of articles are conceived to reduce the duration, and consequently the costs, of on-line connection to the service. Accessibility means access at reasonable and affordable costs. In order to minimize these costs, we made available compressed versions of the newspaper to be downloaded and read off-line. In this case, the connection duration is limited to the time necessary to transfer the file from the server to the client.

There are two compressed versions of the daily newspaper. The first one is the same HTML version available on-line while the second is a special non standard indexed textual version, reproducing the same structure of the HTML version, compatible with a popular reading program used by Italian blind computer users. The two compressed versions can be downloaded upon request (through a command) or can be automatically received by e-mail during the night. This is another facility to satisfy users' requirements.

Feedback from users

At the end of the project (February 1999), we submitted a questionnaire to a sample of users designed to verify their satisfaction with the service and its conformity to their needs. In this questionnaire, we asked users to indicate first of all their personal data (age, education, profession, and experience as a computer user) in order to individualise the profile of the typical user and to be able to correctly interpret other data. A second section was dedicated to pick up data on the experience of access to the Internet and the software used for the navigation. A third section concerned the investigation on service use modalities. Finally, users were requested to comment on the effectiveness of the proposed solutions to navigate and to read the newspaper, and to assign a score to each item of a list of features.

The replies can be summarized as follows. The average age of users is 42 years, with about ten years of experience as computer users, most users have a good education level (university 48%, high school 48%). Everybody uses a speech synthesizer and 30% of them also use a Braille display. Everybody works in a DOS environment and about 50% also use Windows 95/98. Most of them use *Parla* (the most popular screen reader for DOS in Italy) while the preferred screen reader for Windows is *Jaws*. About 70% use the Internet daily while only 10% use it less than twice a week. The most used browser is *Nettamer* (60%) followed by *Internet Explorer* (30%). Only 50% use the electronic newspaper daily while 10% read it only two days per week or less. Most users prefer to download one compressed version (50% textual, 30% HTML) and read the newspaper off-line. On-line readers very much appreciate the additional facilities available on the server. Most users (70%) completely read at least ten articles and glance at another ten, on-line or off-line. The access time to the service is distributed during the day but with a prevalence of the morning, 40% before 8 am.

Discussion

Users' comments and remarks offer some interesting subjects of discussion. Navigation facilities have been appreciated, particularly the ones enabling quick selection of any article. People who are not used to hypertext navigation discovered this was a powerful way to access a structured text. Other users who were more expert even appreciated our organization of the newspaper compared to other newspapers available on the network. The independent active access to a daily newspaper, with the freedom of choice among subjects and articles, has been appreciated and considered more effective and interesting than passive listening of radio or television news. This aspect is generally considered of basic importance in order to go more in depth on subjects of personal interest and to improve one's personal culture. The electronic version of a daily newspaper is the only way to make this type of periodical accessible to blind readers. So far, only monthly or weekly periodicals have been available in an accessible form, consisting of a cassette edition produced by the different talking book services. Another aspect appreciated by users is the availability of the newspaper at the beginning of each night, generally at 1 or 2 am, including during week-ends and holiday times. This has been possible thanks to a completely automatic processing of the material sent every night via e-mail from the editorial office of the newspaper in Turin to our Institute in Florence. The material is loaded on the server machine and filtered and converted in several steps to the final version made available for users. It is not possible to describe here this complex tomatic process. However, we can emphasize its strength and reliability, obtained after a long testing phase in which we fixed any software bugs and we have introduced many features to overcome a large variety of problems caused by frequent irregularities in the encoding of the original materials. As a result, the electronic newspaper service is highly reliable thanks to the professional organization of both hardware and software configurations. This represents an important feature compared to other services for the blind available in Italy, where volunteers manually convert materials downloaded from other sites into electronic documents. This work is subject to the availability of such volunteers and cannot ensure the availability of daily articles early in the morning.

Some users were not able to use the HTML structure for local reading of the downloaded newspaper form of our service. This is caused by a lack in the navigation capability of their browser's old releases. Generally, these are special browsers conceived to simplify installation and use by a blind person. These tools cannot generally be flexible and effective enough to ensure adequate performances in any situation. Even if we tried to take into account these limitations, as mentioned above, we did not want to impose the same limitation on users able to use more advanced browsers, in the name of a general low level equality. Our service would rather encourage the adoption of more effective tools in order to improve the personal navigation possibilities, not only inside the newspaper but more generally on the network. To ensure local effective navigation inside the newspaper for everybody, we made available a special textual version as mentioned before. This solution, even if it allows a blind person to select articles by means of a structured index, organized like the HTML version, does not represent a standard format. The preference of many users for this textual version frustrates our attempts to encourage blind people to improve their autonomy in accessing information via the Internet by using more advanced and standard browsers, such as graphical ones, that are now accessible for them by means of effective screen readers.

However, off-line reading appears to be an important aspect of access to daily information by blind people. In particular, some users emphasized the possibility of expanding the compressed textual version of the newspaper on a special pocket notebook equipped with speech output, in order to be able to read it on the bus or on the train, as sighted travelers usually do with the printed newspapers.

The problem of standard versus special hardware and software arises again. This dilemma is related to any application of assistive technology. There are two fundamental approaches: the development of completely special and dedicated systems or the adaptation of the existing commercial ones. In the case of electronic texts, we can design special formats, to be easily read by blind people or make these readers able to access standard formats in order to ensure the technical integration of blind people. Again, when the access to a standard format requires a suitable program, such as an HTML browser, this program can be developed in a special version for blind people or a standard one can be made accessible by means of a screen reader, like any other application. In our opinion, whenever possible, the second approach is the best one since it ensures the use of generally more effective products which can be shared with other people, regardless of their ability. Special solutions should be reserved for cases in which no possibility exists to use standard sources or tools.

In the case of the access to a newspaper, this principle leads to the choice of a standard format, such as HTML, using a standard hardware platform, such as a desktop, laptop or palm top device, with a standard operating system made available with a suitable screen reader, in which a standard browser can be effectively used by a blind person. This is possible today even in the case of small portable machines since software versions of speech synthesers, running on a standard multi-media hardware/ software configuration, are available, so that no additional hardware component is necessary.

Nevertheless, many blind people continue to be attracted by customized hardware and software solutions. This attitude is probably caused by the difficulty of learning new procedures that require a training phase, with the assistance of an expert. This is a rehabilitation problem which is generally underestimated. Many blind people prefer to keep using well known devices and programs rather than try to improve their ability and possibility of independent access to more advanced tools.

Future developments

The electronic daily newspaper service could evolve in several ways. If we just look at the WWW sites of the main daily newspapers available in Internet, we see that they are generally enriching more and more of their contents. In many cases starting from the electronic version of the printed newspaper additional information is made available such as real time news, topic deepening, databases, reader's forum, etc.

It could be observed that, according to the above expressed principle, the best solution would be to make blind people able to directly access these information sources rather than to develop a special site. This is a more general problem that concerns the accessibility of HTML pages and WWW sites. Many organizations are studying this problem. We can mention the WAI[2] project of the W3C Consortium which is releasing guidelines dedicated to authors, tool developers and companies of assistive technology, in order to spread knowledge about accessibility. Unfortunately, this principle and culture is not yet accepted by society so that we often find inaccessible WWW sites and this justifies the development of special sites for blind people.

Incidentally, it can be observed that our service of an electronic daily newspaper is an open service for everybody, regardless of the sensorial or physical ability, rather than a special service for blind people. It is an example of application of the 'design for all' principle.

The main users' suggestion was the extension of the service to other newspapers. This is not easy because of the difficulty of obtaining the cooperation of other publishers. In many cases they have not developed electronic material delivery and, even if they do, the most favourable condition is the free availability of such materials with no processing charge for them, either from the financial or from the technical point of view. This means that the whole software development and management of the special version of the newspaper must be supported by the service. In particular, each newspaper generally uses a proprietary code and format for its electronic materials. This requires a dedicated transcoding program.

We organized the transcoding process of the newspaper in such a way as to simplify the extension of the service. In particular, we adopted a meta-format, which does not depend on the original code of the newspaper, from which we generate the different format made available for end users, that is the HTML and the indexed textual formats. This means that to add another newspaper we just have to develop a transcoding program to convert the original version into the meta-formatted one. This reduces the amount of necessary work by avoiding duplicating the complete transcoding up to the final format.

The adopted meta-format is an SGML (Standard Generalized Mark-up Language) version established by the European TIDE-CAPS[3] project as a European Interchange Format for accessible newspapers. This standard has been established to make the interchange of newspapers materials easy but, unfortunately, publishers have not yet accepted this so that the problem of encoding differences remains as an obstacle. However, the adoption of this standard in our service simplifies at least the internal transcoding.

Other users suggested the production of personalized compressed versions of the newspaper, with only articles of preferred subjects, in order to reduce the transfer time of the file. Other suggestions concern the availability of a database of previous issues of the newspaper. All these requests will be taken into consideration for future developments, depending on the availability of resources.

Conclusions

The experience of the organization of a distribution service of an accessible electronic newspaper demonstrates that such a form of information source is necessary to ensure blind people have access to daily information, because of the accessibility limitations of the sites made available by many newspapers.

A careful design of such a service required some special functions to improve the effective navigation and reading, which have been appreciated by users. This kind of service can be enriched by taking into account the real users' needs.

Blind people can benefit very much from the new opportunities made available by technological development but it is necessary to encourage the adoption of the most advanced hardware and software tools in order to fully use new information sources.

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[1] Bobby: http://www.cast.org/bobby

[2] WAI: http://www.w3.org/WAI

[3] CAPS: http://www.esat.kuleuven.ac.be/teo/Resproj/CAPS/caps.htm

Computer work in sheltered employment: a systematic approach for qualification

by Klaus J. Zink, Frank Leidermann and Harald Weber

Abstract

For people with disabilities, computer work offers a lot of opportunities for adequate occupation. This paper describes an approach of how to evolve and conduct accordant qualification measures. The concept includes an analysing methodology regarding task requirements and individual abilities. The approach has been developed and evaluated in cooperation with German and French sheltered workshops and vocational rehabilitation centres.

Background

In Germany sheltered workshops are defined as institutions dedicated to vocational (re)integration of those people with disabilities who can not be employed in the open labour market. The workshops' two-fold mission is to offer adequate occupation and qualification on the one side, and to provide individual development potential on the other. In Europe, a variety of similar institutions[1] exists, which differ regarding economic performance, rehabilitation approach and degree of public influence (see Diagram 1).

Keeping the workshops' two-fold mission in mind, for certain employees computer work constitutes a beneficial alternative to traditional working fields. On the one hand, physical load is relatively low, on the other hand, sensory or motor limitations can often be compensated. Besides, there is obviously no doubt about the market demand for computer services.

The question is how to initiate and establish such computer groups in sheltered workshops? This question led to a research project carried out by the Institute of Technology and Work at the University of Kaiserslautern and two pilot workshops (Weber & Zink, 1998).

According to the socio-technological system

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[1] Some examples for these institutions are (Arnold & Larisch, 1997): Beschutte Werkplaatsen/Atelier Adapté (B), Beskyttede Vaerskteder (DK), Työkeskus, Toimintakeskus (SF), Atelier Protégé, C.A.T. (F), Werkstätten für Behinderte (D), Verndaöur Vinnustaöur (IS), Sheltered Workshops (GB), Laboratori Protetti (I), Sociale Werkvoorziening (NL), Arbeidsmarkedsbedriftene, Arbeidssamvirketiltakene (N), eschützte Werkstätten (A), Centros de Emprego Protegido (P), Samhall AG (S), Centros Especiales de Empleo (E)

design (Rühl, 1974) organizational, personal, and technological, as well as economical and legal aspects were considered. Personal aspects, especially the qualification of the employees were revealed as one crucial success factor.

Consequently, a follow-up research project was launched in 1998, called CAPADAPT.[2] To overcome a narrow national focus this project was designed as a European project. The partnership includes French and German workshops and rehabilitation centres as well as the Institute of Technology and Work. In the following the project's qualification approach is specified, including the developed analysis methodology.[3]

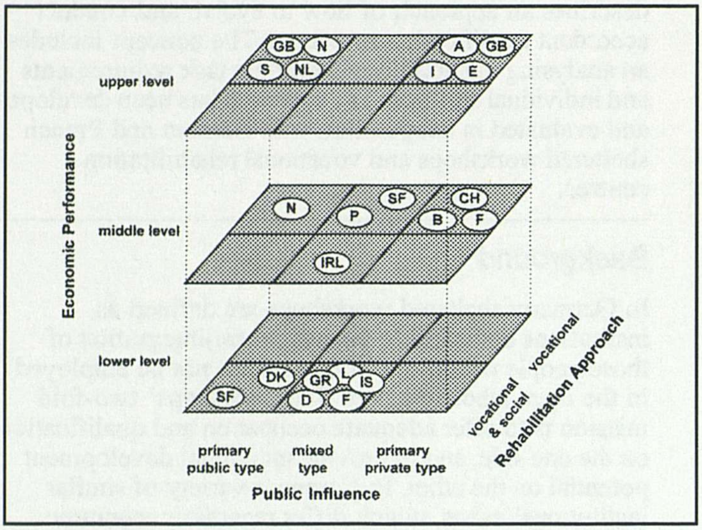

Diagram 1: Different workshop types in Europe (Arnold & Larisch, 1997, p.38)

Analysis methodology

The target group of CAPADAPT is highly heterogeneous. It comprises people with motor, cognitive, learning or mental health disabilities, in most cases even with multiple disabilities. Therefore, the detailed assessment of an individual's abilities and respective potential is fundamental for adequate qualification. This assessment is complemented by an analysis of working task requirements as the training has to be orientated to relevant working activities in order to fulfil economical constraints.

Within the project, an accordant analysis methodology was developed which is founded upon an already existing approach (Kleffmann & Weinmann, 1998). Diagram two shows the concept of this methodology.The workshop staff, especially the carers (working team leaders) and the special pedagogues, are confronted with two fundamental questions:

1. Which working tasks are feasible for an individual employee? (job assignment plan)
2. Which learning objectives are mainly important for an individual employee? (training plan /curriculum)

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[2] CAPADAPT is co-financed by the European Social Fund and the state Rhineland-Palatinate in the framework of the European Community Initiative ADAPT.

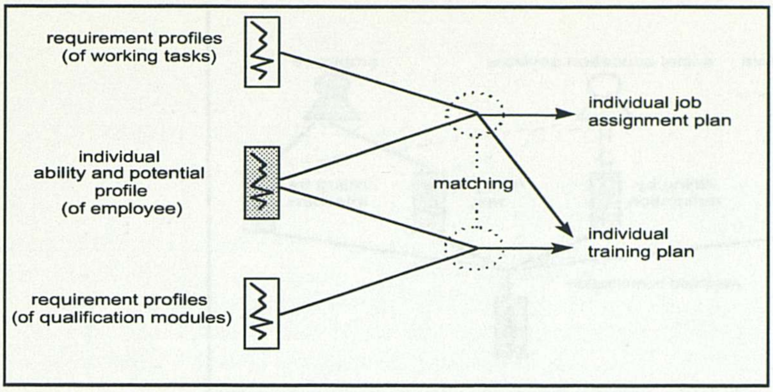

Diagram 2: General concept of the developed analysis methodology

Obviously, both questions depend on the abilities and potential[4] of the individual employee on the one hand and on the working task requirements on the other hand. The second question additionally deals with the requirements of different qualification modules.

Consequently, the analysis procedure comprises an assessment and a comparison of requirements and individual abilities. In order to allow systematic comparison, abilities and requirements are represented by 30 corresponding items. These items refer to basic abilities and requirements (see Table 1). Each item is precisely defined. Moreover, for each item a 3 or 5 point assessment scale was developed within CAPADAPT.

The analysed task requirements refer to 'model tasks' (e.g. 'Data-entry of hand-written text') which are typical for computer work in sheltered workshops. The 20 model tasks being identified within the project broadly cover this working field. According to the 30 item definitions, the workshop-specific requirements of each model task were estimated by the working team leaders. In a similar way, the requirements of each qualification module (e.g. 'Hardware-handling', see section 3) were rated by the responsible trainers.

Cognitive capacities	Social capacities	Capacities concerning Manner of Work	Psycho-motor capacities	School Knowledge/ Communication	Place of Work
Work Planning	Self-Assertion	Perseverance	Drive	Reading	Common room
Perceptiveness	Leadership	Critical Control	Minute rotor activity	Arithmetics	Separate room
Attention	Social capacity	Orderliness	Reaction	Writing	
Concentration	Critical faculty	Punctuality		Speaking	
Learning/ Memory	Tolerance of criticism	Independence			
Problem solving	Teamwork	Thoroughness			
Adaptability		Responsibility			
Abstract thinking					

Table 1: The 30 MELBA items (Kleffmann & Weinmann, 1998)

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[4] It should be noticed that the analysis methodology focuses on abilities instead of deficits.

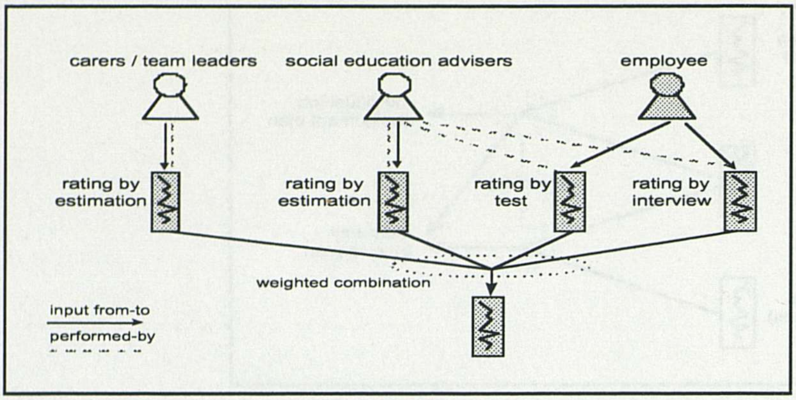
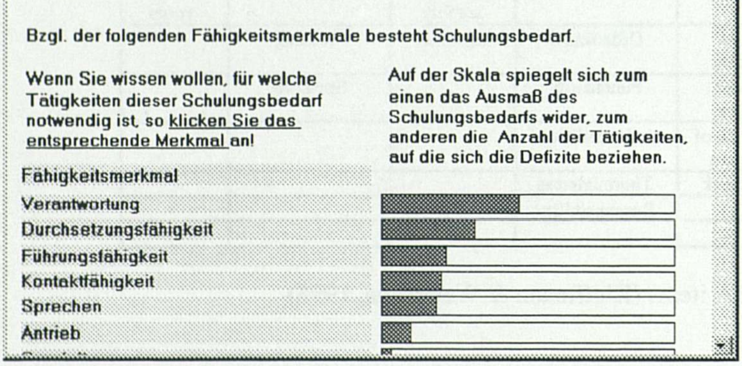


Diagram 3: Assessment of abilities and potentials

Four parallel strategies are used for the assessment of the employees' individual abilities and potentials (see Diagram 3). Carers, working team leaders and social education advisers conduct an estimate based on their knowledge of the employee. A semi-structured interview with the employee and a test exercise are used to collect data for further ratings. The four results are combined to an individual ability and potential profile.

The complete assessment procedure is carried out by the workshop staff themselves, so that the economical effort can be minimized. Within CAPADAPT, detailed guidelines and the necessary form sheets have been developed and successfully applied.

Moreover, a software tool for automatic processing of the analysis data was designed and implemented. The various analysis results are presented on-screen in detail and can be printed out for documentation purposes. The example screen shot (see Diagram 4) shows the most significant qualification needs of one employee.



Auswertung: HGD

Schulungsbedarf

Bzgl. der folgenden Fähigkeitsmerkmale besteht Schulungsbedarf.

Wenn Sie wissen wollen, für welche Tätigkeiten dieser Schulungsbedarf notwendig ist, so klicken Sie das entsprechende Merkmal an!

Auf der Skala spiegelt sich zum einen das Ausmaß des Schulungsbedarfs wider, zum anderen die Anzahl der Tätigkeiten, auf die sich die Defizite beziehen.

Fähigkeitsmerkmal
Verantwortung
Durchsetzungsfähigkeit
Führungsfähigkeit
Kontaktfähigkeit
Sprechen
Antrieb

Diagram 4: Screen shot 'Qualification need' (German version)

The analysis results are not merely used for documentation purposes but also for the planning of individual qualification measures. This is described in the next section.

Qualification concept

Three different kinds of (individual) analysis results can be distinguished. In the following, these three points are specified and illustrated by the short case example of employee Ms. X (*in italics*):

> 1) *The ability and potential profile:*The scope of an employee's ability and potential profile can be focused on the different qualification modules in order to consider special needs during the training.
>
> *Imparting qualification module 'Hardware-handling', the items 'Minute motor activity' and 'Reading' are crucial requirements (besides other ones). Concerning these two items, the assessment of Ms. X' abilities resulted in the rating 'highly restricted'. Consequently, this must be considered within this qualification module.*
>
> 2) *A categorization of the model tasks:* For each employee, the 20 model tasks are divided into three categories of tasks which are:
> a) already feasible for this specific individual,
> b) are not yet feasible because of some learning deficits and
> c) are probably never feasible because of the assumed potential limits.
> Obviously, the individual training courses should mainly cover tasks of category a) and b).
>
> *The model tasks 'Putting on/off devices' and 'Data-entry of machine-written text' are already feasible for Ms. X. The task 'Creating Web pages' seems to be never feasible because of Mrs. X' highly restricted potential regarding 'Abstract thinking'. Concerning the remaining 17 model tasks, there exists various learning deficits but these tasks may be feasible after training.*
>
> 3) *The general qualification need of the employee:* The learning deficits mentioned in category b) result in recommendations concerning the qualification need referring to ability items (instead of working tasks)
>
> *The most significant qualification need of Ms. X includes the abilities 'Concentration', 'Critical control' and 'Independence'.*

Both, the above described 'qualification need' as well as the 'model tasks' of categories a) and b) are imparted within the didactical framework of nine qualification modules (see Diagram 5). These modules represent rather abstract learning objectives, being derived from national framework agreements concerning vocational training in sheltered workshops (Bundesanstalt für Arbeit & BAG WfB, 1996).

During a stepwise, participatory process, these nine modules have been elaborated to detailed but flexible curricula. This process includes different brainstorming techniques in order to take advantage of the working team leaders' and trainers' experience. The final learning materials comprise excerpts of existing literature as well as material created within CAPADAPT. The qualification contents are partly available via Intranet or Internet in order to additionally support self-determined training.

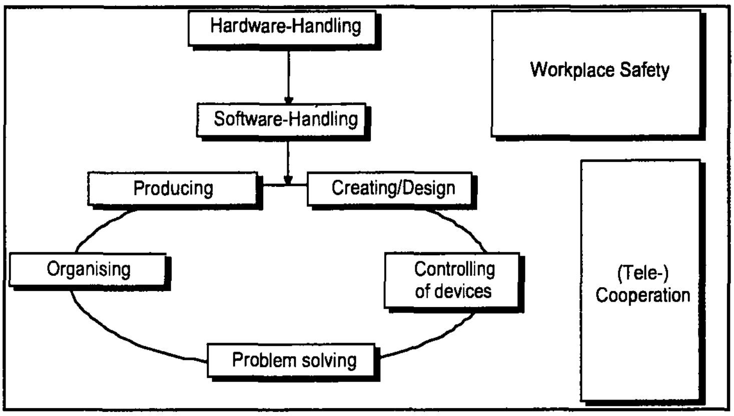


Diagram 5. The nine qualification modules

The qualification measures are carried out within the sheltered workshops and rehabilitation centres by carers and special trainers. Depending on individual needs, 1:1-courses or group courses are offered. The individual learning progress is documented by form sheets being designed correspondingly to the developed qualification curricula.

Prospects

The first experiences with the described analysis approach were encouraging. The methodology as a whole contributes to reducing the gap between analysis and qualification process. Concerning the effectiveness of the training measures, the main hindering factors seem to be economic and organizational constraints within the workshops, especially (temporary) limited personal resources.

In order to identify systematically the key factors for successful vocational training, the project is accompanied by continuous evaluation in France and Germany. The evaluation includes specifications of the assessment and training methods and results, of the different working fields and target groups as well as of the legal, economic and organizational framework.

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Rehabilitation information system for people with disabilities

by Alexander Shoshmin, Natalie Martynova and Anna Riabokon

Abstract

Russian government policy is to organise services for disabled people, but these intentions are not enough. Implementation depends on organisational, financial and legal aspects. It is possible to change the present system of assistance now. For this purpose it is necessary to create a uniform information environment for and about disabled people. This system should unite organisations working with disabled people in regions and enable communications between them. An information network to activate existing resources, reduce expenses and free specialists for individual work.

Russia has one of the highest social budgets in the world as a percentage of incomes. Despite this the state can't meet its obligations in many aspects of social welfare, including rehabilitation of disabled people. In this case, it is caused not only by limited finances, but also by deficiency of information about opportunities for rehabilitation of disabled people.

In this paper we present a clear and constructive program for practical realisation of an information system in one social sphere – rehabilitation of disabled people.

Introduction

According to "Standard Rules on the Equalization of Opportunities for Persons with Disabilities" the term 'rehabilitation' (accepted by General Assembly UNO December 20, 1993)

> *refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence.*

Rehabilitation can include measures for provision and/or restoration of functions either by compensation for functional restrictions or lost or absent functions. The rehabilitation process doesn't assume provision of only medical aid. It includes a wide list of measures and activity beginning from general rehabilitation and continuing a purposive activity, for example, restoration of vocational ability to work.

Such understanding of the term 'rehabilitation' is slightly wider than in the *"Law of social security of disabled people in the Russian Federation"* (Russian

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Government, 1995), however it doesn't contradict it. According to this law the rehabilitation of disabled people is a system of medical, psychological, pedagogical, social-economic measures directed to remove, or compensate as far as possible, restrictions to life activity, caused by medical or functional impairments. The purpose of rehabilitation of a disabled person is restoration of a social status, and achievement of material independence and social adaptation.

The individual rehabilitation programme

According to the "Law of social security of disabled people in Russian Federation" rehabilitation includes:

- Medical rehabilitation which consists of:
    - restoration therapy,
    - reconstruction surgery,
    - providing artificial limbs;
- Vocational rehabilitation:
    - vocational orientation,
    - vocational education,
    - adaptation in the professional working sphere,
    - provision of employment;
- Social rehabilitation:
    - social orientation,
    - adaptation in daily life.

The practical realisation of rehabilitation process should be based on the preparation of an *Individual Rehabilitation Program (IRP)*. In Russia development of this program and control of its execution are assigned to a state *Service of Medical-Social Expertise (MSE)*. There is a provisional program of rehabilitation (*Federal Base Rehabilitation Program - FBRP*) recommended by the Russian Labour Ministry and some variants of this program have been developed in regions. However when a specialist tries to develop a real IRP they are confronted with some problems. These problems can be divided in three groups: judicial, financial and organisational.

- Judicial problems occur because there isn't a regulated legislative system of rights of disabled people and of duties of social service providers.
- Financial problems are obvious but they are intensified by a lack of information for rehabilitation specialists about rights of disabled people on financial assistance and about financial sources for social services providing obligatory rehabilitation measures.
- Organisational problems are connected with a lack of information about different social service providers working in rehabilitation and can be solved often at a regional level.

According to the *"Law of social security of disabled people in Russian Federation"* an IRP is a package of rehabilitation measures, optimised for a disabled person, that includes: assessment of disability, its degree and a prioritised list of remediation measures; including medical, vocational and social actions to restore the individual's ability to take part in society.

Public authorities, municipal governments and all public, private and voluntary organisations are obliged to execute an IRP. An IRP specifies rehabilitation measures that are free for disabled people according to the FBRP, and rehabilitation measures, which either the disabled person or other public or private organisations fund.

An FBRP is a guaranteed list of minimum rehabilitation measures, aids and services provided to a disabled person by the federal budget. The Government of the Russian Federation authorises an FBRP and orders its completion. Municipalities have to fulfil and can expand its local features and resources. As a rule rehabilitation technical aids and services for disabled people have a physical form.

The extent of rehabilitation measures provided by an IRP cannot be less than a level fixed by the FBRP. The IRP is recommended for an individual who has the right to refuse any kind, form and amount of rehabilitation measures, and also the program as a whole.

A person has the right to solve independently the problem of maintenance itself, a physical aid or form of rehabilitation, including car, wheelchair, artificial limb, orthopaedic footwear, and other special equipment. However, for this purpose he/she would have free access to information (nomenclature of services and technical aids; their costs; terms of performance or manufacturing etc.).

The main problem of rehabilitation

The main problem of rehabilitation of disabled people consists in the complexity of achieving complete integration of a person and society in modern conditions.

The main reasons for this problem are:

1. Absence of a general consistent State rehabilitation policy which should include: development and information support (dissemination) of general social ideas including specifically:
    - idea of equal rights and responsibilities of a disabled person in society;
    - social significance of work (for example, propagation of the advantages of using disabled people as employees to perform some kinds of work);
    - struggle against dependant positions of disabled people;
    - policies to have quotas of job places on enterprises, flexible system of tax discounts and privileges for such enterprises;
    - monopolisation or priority right to be employed in some kinds of work that have no barriers for the majority of disabled people;
    - creation of specialised job places, organisations and industries for disabled people;
    - continuing mass educational policies among disabled people;
    - medical aspects of rehabilitation;
    - psychological support of rehabilitation processes;
    - certain social policies;

2. Absence of an integrated IRP with all necessary attributes of the program stages, terms of their performance, control of performance, connection between stages, persons responsible for performance of the program as a whole and of its separate parts.

3. Absence of a process for tracking a person through a rehabilitation program from the time of recognising a physical impairment to the time when either there is a successful completion of a programme of rehabilitation or it needs re-appraisal because it is not successful.

Need for an information infrastructure

All these factors are impacted by the overall absence of an infrastructure providing access to information resources within the rehabilitation system. This makes it impossible to support the operation of a uniform rehabilitation system and provide necessary information to experts working with and for disabled people.

Currently there isn't an information record of rehabilitation of disabled people as a single whole, it is submitted only in fragments. There are no organised streams of the operative information between executors of separate parts of the rehabilitation process. In the main information streams exist in paper format as statistical reports about the activities of different organisations and establishments and are not invoked to support the rehabilitation process.

For example, there is an organisation which provides home helps to severely disabled people in the city. This organisation is not able to identify those most in need of their services and cannot plan ahead. There is no summary information about functional insufficiency in combination with real social conditions of relevance to disabled people. As result there are huge numbers of citizens deprived of attention who require one-off or continuing social assistance.

The same thing occurs in specialised educational establishments for disabled people. Data about vacant places come to the *Service of Medical-Social Expertise* (MSE) office weekly but only in term time and are distributed inside the city where these educational establishments are placed. Data on availability of job vacancies for disabled people are in employment services, but firstly this information is not distributed widely (not always received even in the MSE office), and, secondly the job description is not always completed fully to indicate that the job would suit a disabled person.

Consider the detailed situation of an adult disabled person who requires education as part of the rehabilitation programme. A disabled person can be directed to an educational establishment only if assessment of his/her state of health takes place during enrolment time. According to the data of one MSE, St. Petersburg office, 40 people decided to undertake education in 1997. In reality only eight started education and only five completed courses. Thus one eighth of the directed people received additional specialised training. The experts of MSE office are not able to provide information about other resources of specialised education, vacancies on labour-market, demands for particular professions and to realise equal possibilities in education because there isn't a system of gathering and giving information to specialists.

One of the sources is an information stream of normative and methodical documentation distributed centrally. It comes regularly. However, the quantity of these materials and often its quality cannot be considered satisfactory and does not provide necessary methodical and actual information of each participant of the rehabilitation process.

An information framework

The current state of affairs has arisen because no-one has conceptualised the activities involved in rehabilitation and identified the information needs.

The absence of information assurance for disabled people means that the rehabilitation process begins to work only when a disabled person (or his/her representative) appeals for assistance. Currently suggested programs of rehabilitation are limited by general recommendations, because there is not often detailed authentic information. Procedures for control and evaluation of results of rehabilitation are virtually absent too.

It is obvious firstly that all this information should be accessible at the MSE office. Moreover according to the legislation, an MSE office should be able to track the process of rehabilitation for each disabled person with the purpose of evaluating the results of rehabilitation and correcting the IRP.

In order for executors of IRPs (participants in the rehabilitation process) to plan their work rationally, the information about evaluation of this program should come operatively to them. Only thus it is possible to make best use of available resources without additional, huge investments. The principle is to change present practice of work of the MSE offices and rehabilitation establishments.

Thus, now it is necessary to consolidate all data about a disabled person in general information terms, accessible for all developers and executors of IRPs at any level. The information system for rehabilitation developed on the modern scientific and technical level should aim to provide essential data for both developers and executors of IRPs. The Information system for rehabilitation should provide an opportunity to achieve the main purpose of the rehabilitation ideal (as expressed in the UNO definition).

Various kinds of rehabilitation of disabled people are an integral component of the IRP. Accordingly such kinds of rehabilitation as medical, social, vocational, psychological, educational and other are connected closely between themselves. The core information ensuring a rehabilitation process is common, however in each case there is also specific information for every kind of rehabilitation. The level of information security depends on each type of rehabilitation: at first this is connected with organisational and legal working conditions.

Developing an information system

Analysis of available materials and consultations with experts have shown, that current methods of assessment, storage and receiving of information do not provide an opportunity to develop and effectively carry out an IRP.

On the one hand the state has no figures for the number of disabled people in the Russian Federation and what their requirements are, or on the other hand what resources for satisfaction of these requirements the state has. As result it is not known if there are enough resources or not.

Thus, for the decision of rehabilitation problems it is necessary to organise the assessment, analysis and information interchange between all interested organisations and departments in the following ways:

- identifying disabled people;
- assess requirements of disabled people;
- technical aids and services;
- medical rehabilitation;
- vocational rehabilitation;
- social rehabilitation;
- psychological rehabilitation;
- educational rehabilitation;
- procedural materials;
- legislative materials.

For this purpose there is to be gathered, stored, processed, and if necessary, transmitted information in the databases about:

- disabled people;
- providers of technical aids and services for various kinds of rehabilitation;
- glossary of rehabilitation aids and services;
- rehabilitation service providers;
- terms of execution of services and services characteristics (start time, duration, steps, minimum base qualification of a disabled person etc.);

- manufacturers of equipment;
- job vacancies, vocational routes etc.;
- demand for labour, skill types: short-term forecast, long-term forecast, etc.

It is necessary to organise communications between all participants of the rehabilitation process. On the one hand, experts should have the maximum information about rehabilitation forecasts (opportunities for a person) and requirements of a disabled person, on the other hand. They have to know how, where and *also by what means* it is possible to develop these opportunities and to satisfy these requirements.

Fulfilment of this approach is possible only by consolidating the information of various organisations and departments (creation of uniform information sets). It is necessary to integrate all participants in the rehabilitation process and provide access to the information to each of them and co-ordinate their activity.

Characteristics of the system

For this purpose an automated system of information security of physical ability problems should be created. One of the most important parts of such a system should be the united automated information and analytical system of accounting and rehabilitation of disabled people (hereafter *System*).

The *purpose of the System* is to:

- ensure and support the social security system of disabled people,
- ensure information resources to specialists working with disabled people by building a general infrastructure that would provide access to information resources.

The *System base* is the corporate store of data. It includes all necessary information. The top level of the System should be created on the main server. At this level using computer network technologies there are formed and supported common databases, such as judicial-legal, technical rehabilitation aids etc. Here information is gathered from lower levels (regional/inter-regional servers), then it is analysed and given to the Labour Ministry of Russia and other interested departments.

A level of regional/inter-regional servers provides the main interactions between departments, organisations and establishments taking part in the rehabilitation processes. A disabled person is registered in the System during their medical-social assessment in an MSE office. These data as well as data from the Individual Rehabilitation Plan are kept at a regional/inter-regional server level.

The main organisations with which data exchange is supported, are social security offices, employment services, specific industrial enterprises, recruiting offices, educational (including specific) establishments, medical and medical-preventive establishments, culture and sports, health-improvement establishments, municipal government offices, and other rehabilitation organisations.

One of the main tasks of the System is the maintenance of development and performance of an IRP. We can note that it is impossible, without the large quantity of reference information in main areas of rehabilitation (medical, social, vocational). There is a separate problem gathering and supporting this information in reality.

Building the system

This System has rather strict constraints for software resources and cost. The analysis has shown that *Caché* software of Intersystem, inc. and *qWord* tool for constructing knowledge bases have an optimum ratio of price/quality. *qWord* tool was made on *Caché* basis by experts SP.ARM (Russia, St. Petersburg).

On this software platform separate System parts have already been completed. Use of *Cache* and *qWord* allows the building of a System with unlimited database size, without rigid requirements to data format that will allow immediate use while developing databases of other systems.

It is important to note that positing of this problem on such a level has become possible only due to new solutions in the field of constructing of information systems. Even the previous generation of possible technical and program decisions (5-8 years back) couldn't resolve this problem on such a level. In this development it is possible to apply lessons learnt from previous implementations of information systems.

Besides the important part of the project, without which it probably will not be possible to receive full feedback from it, is its information maintenance from every service connected to it without dependence on their 'personal' or departmental interest and well-balanced administrative co-ordination of all actions of various services. It is relevant to design period, programming stages, testing and industrial exploitation. So elaboration of the System is done in close co-operation with the Labour Ministry of Russia.

Now on instructions from the Ministry the Institute has started development of the System. One of problems of this System is giving the necessary information to disabled people, experts, to developers and executors of IRP. Until the System is completely implemented it is necessary to maintain the existing paper technology.

The general structure of the System and separate job places has been developed. There is an automated MSE office level (now debugging), a job place for municipal government office and public organisations (Consultant of Inability Problems), basic electronic references, for example "Technical rehabilitation aids", "Classifier of illnesses", "Educational establishments for disabled persons" and some others.

During the initial assessment and creating of the IRP with a person, the impairment and social-economic status are recorded. For this there are created 4 job places at MSE office level with connecting corresponding references. At this level there are selected state-guaranteed rehabilitation measures and privileges for a disabled person on an appropriate kind of rehabilitation (social, vocational, medical).

In addition they are given detailed information about (not paid by the state) rehabilitation measures (security of technical rehabilitation aids and other services in the rehabilitation field) for physically disabled persons. The information about services should be detailed to a degree necessary in practical terms: the detailed description of a service, organization-executor site, terms, cost and variants of payment. The possibility of reservation in the System of the service for this disabled person is foreseen.

Thus, providing the information through the System to an expert during the process of construction of an IRP will allow providers to render effective delivery of assistance to a disabled person at a new level.

Implementation

Implementation of the System can be started from some job places. But it is too long, difficult and expensive a way. It seems better to automate some MSE offices (as key positions of the System) and smaller regions. It is expected that in future employment, educational, health services will be connected to the main part of the System gradually. We are sure that in 1999 we will finish the System at the MSE office level, connections between MSE offices, gathering and analyzing information on the central System server. We hope for the goodwill and help of our colleagues with experience in developing and implementing such systems.

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Virtual networks for language therapy – experiences

by Magnus Magnusson and Marianne Christensen

Abstract

Groups of speech pathologists all over Sweden have worked together to build networks for professional co-operation. Today, about 20 systems are permanently installed and two of the schools for therapists in Sweden are involved giving courses over the ISDN-network. Patients as receivers of therapy on a more general level have also been involved. The technology is based on desktop computers with videophone-cards inside and communication through the ISDN system using 128 kb/s speed. Participants in the projects have tried several different applications, including sharing standard programs over the network at the same time as they participate in a videoconference. The projects are based on research work on language training using videotelephony at the University of Karlstad.

Introduction

Human communication is built on the usage of all our senses. Although speech is popularly considered as being the most 'natural' form of communication, people use more than the oral and auditory channels when communicating with each other. Visual and tactile communication and interaction is important in all cultures even if there are cultural differences as to the relative stress on each channel of communication, in relation to the others. The tactile, olfactory and proprioceptive dimensions of communication seem to have lost importance in the modern information society as distance communication has grown in importance and those dimensions have been almost impossible to reproduce so far. Communication is multifunctional and multimodal in its basic structure.

Auditive distance communication has existed for more than a century, since the telephone was invented. Visual distance communication has existed for even longer, at least in a limited sense. Most human cultures have developed sophisticated visual signal systems over the centuries for distance communication – smoke signals, fires, semaphore, flags, etc. However, the technology involved did not help in receiving those messages from further than the eyes of the receiver could manage, in other words, the body presented biological limitations. However, in modern society auditive distance communication has totally dominated since the invention of the telegraph and later the

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telephone. Since the auditive signal contained less information it has been less demanding on the available technology than visual communication. It has been cheaper to develop auditive distance communication for everyday use than visual distance communication which means that auditive communication has been available for interactive (mass) communication while visual communication has been more non-interactive and limited to groups who have used the technology to give visually based information to receivers through media like cinema and TV. During the last 25 years this mixture of different technologies has begun to be called telematics.

However, since the mid seventies, developers have tried to create integrated audio-visual communication systems for distance communication and today we are on the verge of having a technology which might be called 'picture telephony', or more commonly 'videotelephony'. During the 1990s the technology has started to be available as a commercial mass-market product, especially when 'bundled' as a peripheral to personal computers.

Over the last decade, technology has allowed for the integration of different modes of communication as well as cheaper visual interactive communication. This also means that technology has become more available for all groups of people, including older people and those with special needs, and offers new solutions to old problems of communication limitations for people with hearing impairments, speech disabilities, mental impairments, etc. The Internet, as the most well known application, is offering a seemingly new framework for primarily indirect, non-real time, communication, for people with communication disabilities such as Aphasia (Lifvergren, Lundell, Magnusson, 1997). However, the Internet is not the only public electronic 'virtual transportation network' as will be shown below.

Technology oriented projects in Sweden

Speech pathology in the general sense is a vast field of communication. In that field many projects have been developed during the years, including technological applications. The field of AAC (Alternative and Augmentative Communication) has inspired a large number of technology projects all over the world and in latter years these have focused on telematics projects. Many projects have been initiated in Sweden in the last twenty years but projects involving videotelephony are fairly new in the speech pathology field.

The first large project was a three-year project at the University College of Karlstad, under Professor Irene Johansson, where the aim was to study videotelephone-based language training for language disabled adults, meaning people with Aphasia or mental retardation (Johansson, Magnusson, Wallin, 1997). During most of that time, the Karolinska Institute has managed a course for speech pathologists on computer technology which one of the authors of this paper led. The course has given over twenty per cent of all Swedish speech pathologists a basic knowledge of information or computer technology.

In Sweden there are approximately eight hundred speech pathologists out of a population of 8 million. Forty individuals or 0.5% of them are male so the group could be considered as mainly female. Most of them are working in the big city districts which means that the more unpopulated areas of Sweden, which would correspond to about two-thirds of the country's geographical area are understaffed. For instance this effects about twenty per cent of the population in the northern part of the country, or seven of the 24 counties of Sweden. Speech pathology is a (para)medical profession and the medical services are mainly the business of the county councils while higher education and research is the business of the State and managed centrally. This means that undertaking research activities in the medical or care field can be difficult to organise. However, most local counties support research in co-operation with their closest university or university college. There are also a few university hospitals in

Sweden, situated close to the original five old universities of Sweden. There are four schools for speech pathologists in the country, including the one at the Karolinska Institute.

The authors have been responsible for working on several projects connecting speech pathology with telematics and below we will present some of them, concentrating on videotelephony:

TELELOG, REGLOG

In 1997 Värmland County Council (where Karlstad University is situated) started the TELELOG project, partly with financial support from the EC. Magnus Magnusson has been the project leader for that project and the aim has been to teach all speech pathologists within the County to use videophone equipment as a natural part of their intraprofessional relations. The equipment is based on the Intel Proshare videocard and uses 2x64 kb/s ISDN and allows for LAN-communication and follows H320 and H323 standards. 10 stations are active at the moment and additional stations will be activated within the next few months. The results of this project will decide on the future use of the technology as a more integrated part of the therapeutic part of the work of speech pathologists. TELELOG 2 started in 1998 and concentrates on studying applications for language impaired people and is a direct continuation of TELELOG.

TELELOG 2 studies the interaction between a few people with severe communication problems and their spouses and rehabilitators. One of the users has brain damage and another has a global Aphasia. A local Aphasia chapter is also involved and a folk high school with a rehabilitaiton course for people with Aphasia. The reaction of the users so far is overwhelmingly positive and the project will go on for another year, involving more users.

Another project which is in its initial stage is called REGLOG. The northernmost college for speech pathologists is situated in the city of Umeå, not far from the Polar Circle. During the basic training period a lot of the time is spent in local hospitals or training centres ranging over an area of half of the country entailing both students and staff in a lot of travel. Therefore staff decided to install desktop videophone systems in all of the nine main training places, thereby offering students and supervisors the possibility of interacting without having to travel. The person responsible for the speech pathology school in Umeå is ass. Professor Ms Elisabeth Sederholm. The project is planned to develop a network over three years, including all speech pathologists in that part of the country. So far, three systems are installed and another five systems will be installed in the northernmost area of Sweden in the autumn of 1999.

One way of supporting the participants is to give them education, training or supervision. At the college of speech therapists in Stockholm a post-graduate course has been given on the subject of telematics and distance communication for speech therapists. The course covers 5 Swedish academic credits and provides basic knowledge on the theory and practice of telematics and different methods of distance education. Forty per cent of the lectures are transmitted over ISDN using videophones. The course will result in a report in Swedish, available on the Internet with results from usage of the technology.

There is a common technology and methodology in all of the projects. First of all the common user group is speech pathologists, specialists in communication and problems with speech and language. Secondly, the aim is to develop professional networks, that is, the communication will be very goal-oriented. Thirdly, the technology is desktop-videotelephony meaning that the videophone function is integrated in a standard PC and can be combined with any other of the functions of the PC. Fourthly, the network used is ISDN which is an open network. In other words, a standardised technology is used in a natural environment.

The same type of system has been, or will be, used in all of the projects. The software includes standard word processing, database, graphical and language training software. The hardware of the system includes a 19" monitor, colour printer, flat-bed scanner, CD-ROM, Pentium processor (mostly PII), loudspeakers, a headset and a separate digital still picture camera. The videophone hardware and software also includes the PictureTel 200 system beside the Intel Proshare.

About 40 speech pathologists and 20 students are or will be involved in these projects. So far, 25 professionals have been involved and the response has been very positive. The participants rapidly develop user patterns where they interact on an everyday basis with their colleagues instead of using the phone or meeting physically. Some interactive work has also been done, mostly writing texts together, sharing word processing software between two users. People have also attempted to share therapeutic software, thereby simulating a session with a patient. The next step will be to try and practice therapy through the videophone. The main problem has to do with the experienced conflict of priorities between having to choose between the computer and the patients. However, this problem is not an objective one since some of the participants make their priorities without experiencing any problems. All participating speech pathologists have also been allowed by their employers to take time to participate in these experimental projects.

Conclusion

The final aim of all the projects is fivefold. First we want to establish a well founded description of the quality of the communication situation in relation to its physical counterpart. Secondly we want to establish cost-effective alternatives in the professional care of people with speech and language problems. Thirdly we want to make this technology a commonly used tool among speech pathologists and therapists in the whole of Sweden since its multifunctionality seems to offer new possibilities in our work. Fourthly, we want to evaluate the methodologies which might evolve out of the usage of this technology. Lastly, we want to see in what ways this technology can support and alleviate the social communication patterns of the specialists as well as the service users, in other words, the people with different sorts of communication disabilities.

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Establishment of the network in the field of augmentative and alternative communication (AAC) in Finland

by Tuula Petäkoski-Hult

Abstract

The goal of the project carried out by ISAAC-Finland (International Society for Augmentative and Alternative communication of Finland) has been to create a network between organisations of members using or needing AAC methods in their daily living or work. Usually the membership is often diagnosis based, such as Cerebral Palsy, Stroke, and Muscular Dystrophy organisations. Co-operation between organisations is needed. So far the results have been encouraging.

Introduction

The population of Finland is about 5.1 million and over 30,000 inhabitants have speech disorders (Pulli, 1995). Many of them are members of patient organisations. There are over 20 national organisations supported by local activities and organisations whose members are more or less dependent on AAC in their daily living. Mainly the members of those organisations speak well and understand normal spoken language, but some have members who have difficulties in producing or understanding spoken or written language, e.g. members of the Finnish CP Association and the Finnish Association on Mental Retardation. Many of these people are users of augmentative and alternative communication methods and varying types of technical communication devices. They are dependent on AAC in their daily communication and co-operation with other people. Patient organisations also have members who are specialists in the field of augmentative and alternative communication, e.g. speech therapists, medical doctors, research scientists and other people interested in the area. Because there are so many actors in the field there is a need for co-operation.

ISAAC-Finland was constituted almost ten years ago. The mission of the organisation is to work as a co-operative organisation and to represent the users and others active in the field of AAC. ISAAC-Finland also

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organises courses for speech therapists and AAC-workers. The 150 members of ISAAC-Finland include people working within speech disorders, people suffering from speech disorders using AAC, end users and their parents or other family members.

New development process

ISAAC-Finland realised there was a need for a new activity and the organisation attempted to find funding for the development process needed. The executive board turned to the Finnish Slot Machine Association and the Association agreed to fund the project, *Establishment of the Network in the field of Augmentative and Alternative Communication in Finland,* for a period of 3 years. The funding was 300,000 FIM during 1997, 200,000 FIM in the year 1998 and 300,000 FIM this year.

The aim of ISAAC-FIN is to establish a network between organisations and people who are interested in AAC as end users, research scientists, speech therapists and family members. The basic idea of the project is to increase and develop the activities of ISAAC and to impact on the quality of life of AAC users and their ability to be active members of society. ISAAC-Finland started this three-year process in May 1997. Following tables (1 & 2) emphasises the numbers of people with different kind of speech disorders in Finland (Ahonen & al., 1995).

Diagnosis	**Cases in Finland***	**With speech-motor problems****
Cerebal Palsy	6 500	2 500
ALS	300	200
Muscular Dystrophy	2 500	200
Multiple Sclerosis	5 000	1 000
Myasthenia Gravis	700	10
Parkinson Disease	12 000	8 000
Quadriplegia	500	20
TOTAL	27 500	11 940

Table 1. Speech-motor impaired cases in Finland

* The numbers are from a variety of sources

** Numbers are rough estimates

It is difficult to find out precise statistical data concerning speech disorders, because it is often one character of a diagnosed disability or impairment. The numbers shown in Table (1) are rough estimates. It must be stated that there is a need to develop new methods for collecting statistical data.

It is important to analyse the statistical data a little further and to remember that the population is aging in Finland as it is in every European country. This means that the number of people with stroke and dementia are growing and this will be a challenge for many patient organisations.

(See Table 2 overleaf). The co-operative network between patient organisations will be very important in the future, because it will be possible to organise different kinds of activities. It is necessary to be in contact with different actors during the establishment process. It is also important to use information technology when establishing this kind of network.

Objectives of the project

The objectives of the project were decided by the executive board and were discussed with organisations having members using AAC. All representatives involved in the preparatory process stated that it was necessary to organise an active and functional co-operative network between the private and public sector. It was also realised that the use of the Internet and e-mail offered new possibilities and solutions which should used when establishing a new kind of network between different actors. The main objectives of the project were:

1) to establish a network and co-operation between different organisations;
2) to organise an AAC database for national and international information;
3) to develop education programs in the field;
4) to support AAC users role as a member of the society and,
5) to influence legislation.

Diagnosis	**Cases in Finland***	**With language-cognitive problems****
Stroke	30 000	10 000 - 12 000
Dementia	50 000	2 000 ***
Autism	5 000 - 7 500	5 000 - 7 500
Mental retardation	28 000	8 000
Cerebal palsy	6 500	2 700
Dysphasia	2 000	2 000
Truamatic brain injury	15 000	400
TOTAL	121 000 - 124 000	30 100 - 34 600

Table 2. Language-cognitive impaired cases in Finland

* The numbers are from a variety of sources
** Numbers are rough estimates
*** Not potential communication device consumers

In the beginning of the project it was necessary to decide which target groups should be taken into account. The network should include contacts to the patient and consumer organisations, the Ministry of Education, the National Board of Education, the Ministry of Social Affairs and Health. Also contact with the schools educating personnel for Social Welfare and Health Care were seen as important. The Hospital District, both Special Schools and researchers working in the AAC field were included to the partner list.

Methods

It was realised that the goals could be achieved only in partnership with the other organisations. Based on that reality the consultation methods used were: meetings, seminars and questionnaires. Some were delivered during a technical device exhibition other using postal services as well as e-mail. The project was also described in the membership newsletter of ISAAC-Finland. The aim was to get information concerning the needs of each organisation and also to collect their proposals for future work in the area of AAC. A further aim was also to analyse the lack of knowledge and information concerning the use of AAC methods with disabled patients and end users. Questionnaires were also distributed to 46 schools educating personnel for social and health care sector in Finland.

Because of the international and national trend to build an information society, application of information technology and technology supported communication will grow. This means that most organisations will create their own WWW sites. From this point of view it was decided it was important to establish a web site as a vehicle for delivering the project's aims for ISAAC-Finland. Members commented on the site and opinions of other partners were collected. The structure was planned based on the answers and guidelines received from the members of executive board of ISAAC-Finland and some co-operating partners.

The web site includes general information about ISAAC, a list of books available for loan from the library and a short description of some communication methods. Presented methods are Bliss-symbol language, PIC Signs and Sign language. Some technical communication devices are described on the web pages as examples, also. The idea is that the users of the web site could give feedback to enable further development.

Results

Through the establishment process many ideas for further work has been received. These ideas will inform future work and have already affected current activity. One concrete proposal has been that the web site of ISAAC-Finland could work as a general information source or center for the network. The web site is allowed to link with the sites of other organisations. Some of the partners said, that the web pages are good enough to assist their students writing seminar papers during their education as AAC-workers. They were of the opinion that it is important to have information flow in both directions, between organisations and between end user and different organisations. It was also found that the accessibility of the information services offered by ISAAC have increased too.

The analyzed results achieved by the consultation methods show that there is a need for different kinds of educational activities, courses and workshops concerning AAC. According to many answers there is a need for very practical education and workshops, which should be carried out together with AAC users. Workshops together with end users using computer based communication devices are also desired to enable the practise of the use of computer based communication together with real AAC users.

At the start of 1998 a representative of ISAAC-Finland presented a statement to the Committee of Education of the Finnish Parliament. The aim was to influence to the government proposals for education, especially for the special education arranged for disabled children. Matters concerning the availability of technical devices for children were also considered in the statement.

The development process has shown that there is a need to establish conversation pages on the web site too. Conversation pages (Chat rooms) could offer a new way for people with communication problems to find new friends and new ways to impact on their services. ISAAC-Finland is currently looking at alternatives to answer this challenge.

Discussion

ISAAC-Finland started this project because it was found there was a need for information and education in the AAC field. It was also realised that with this project it is possible to positively effect the real life situation of AAC users and their families. On the basis of the results achieved during the last two years it is possible to develop our work and the activities of patient organisations, too. One very important result is the education plan and programme for specialists working in the field and for AAC users themselves and other people interested in this field.

Today it is important that different kind of services are available. Information technology offers many possibilities to widen the world of disabled and handicapped people. Therefore more attention must be paid to the services offered through the Internet and web sites. There is also a need to use new models to combine a group of actors on the same network whether the network is based on technical solutions or not.

In the future it will be important to establish several networks. By networking we can spread our scarce resources and act more effectively. It is important to take into account the costs and effects of cooperation, but it must be taken into account that all benefits and effects cannot be discussed in monetary terms.

The quality of development processes is important. Because of the information flow it is necessary to inform user organisations and other partners about what is going on when developing a new network. Because of the scarce resources on the AAC field we must pay more attention to further development work both on a national and international level.

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Videoconferencing in psychiatry

by Marja-Leena Mielonen, Juha Moring, Arto Ohinmaa and Matti Isohanni

Abstract

In Northern Finland the long distances constitute a notable problem in the co-operation between primary and specialised care. Videoconferencing has been used for family therapy, patient care planning negotiations, occupational counselling, consultation and teaching. In our case the conventional negotiations cost twice as much or as the videoconferencing alternative. 90% of the respondents were satisfied with the quality of the communication via videoconferencing.

Introduction

In 1995 staff at the Department of Psychiatry of the University Hospital of Oulu established a system of videoconferencing in co-operation with two regional health centres and two educational establishments. Later in the year the Northern Ostrobothnia Hospital District defined the following objectives for telemedicine services:

1) to strengthen the position of basic public health services by use of telecommunications for distance consultation and communication between organisations;
2) to create an integrated distribution system for public health service facilities (based on the provision of the best expertise available at the time, treatment co-operation and cost-effectiveness);
3) to improve the quality of shared information and data production (reliability, speed, ease of use, compatibility and confidentiality);
4) to create a reliable infrastructure (sufficient resources, appropriate confidentiality and accessibility) (Ohinmaa et al, 1997).

Some of the first telepsychiatry experiments in Finland were carried out at the Department of Psychiatry of the University Hospital of Oulu, where videoconferencing has been used for family therapy, patient care planning negotiations, occupational counselling, consultation and teaching (Mielonen et al, 1996). Experiences and results of the videoconferencing in psychiatry have been encouraging. In 1997 videoconferencing was used for a total of 434 hours and it decreased to 406 hours in 1998. During 1998, 35% of the time was used for teaching,

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24% for occupational counselling, 21% for consultations and therapies, 20% for training and administration and testing the connections.

The existing evidence of cost-effectiveness of the telepsychiatry derived from these studies is poor (Grigsby et al, 1995, Baer et al, 1997), however, since from the published articles in the speciality none of them have used any randomisation, and the sample sizes have mostly been small. Critical appraisal is required to determine the primary areas of application in terms of economy and effectiveness (Ohinmaa et al, 1997, Grigsby et al, 1995, Baer et al, 1997, McIntoch and Cairns, 1997).

In the sparsely populated Northern Ostrobothnia area of 360,000 inhabitants there are very long distances between the Oulu University Hospital and many municipalities. Videoconferencing provides an easy, fast and relatively inexpensive method of providing psychiatric services over long distances. The present pilot survey was done to test the telemedicine assessment model (Ohinmaa et al, 1997). In Northern Finland the long distances constitute a notable problem in the co-operation between primary care and specialised care. The knowhow and support of specialised care is valuable to primary care when they try to improve and reorganise their psychiatric outpatient services.

Material and methods

The aim of the study was to assess the feasibility and the costs of videoconferencing in psychiatric patient care planning negotiation and consulting with primary care. The data was collected by questionnaires presented to the personnel, relatives and patients after sessions. The data were produced by 124 respondents, of whom 13 were psychotic patients, 14 relatives and 97 staff members. The experimental assessment model consisted of the analysis of costs, effects, technical properties, and quality of care. The questionnaire consisted of questions concerning the socio-demographic variables, previous use of videoconferencing, technical quality of the voice and picture, quality of communication, in outcome of the videoconferencing negotiation compared to conventional patient care planning negotiation, and the travelling time and costs involved in videoconferencing. In addition, the respondents' willingness to participate in another videoconferencing negotiation was asked together with the reason for their preference for either videoconferencingVC or conventional negotiation.

Informed consent

The study was approved by The Ethical Committee of Medicine, University of Oulu and Oulu University Hospital. Participation was voluntary and based on respondents' interest. Informed consent was obtained from all participants.

Costs

The total medical costs consist of fixed and variable costs, and the variable costs depend on the level of access to the services. The main source of fixed costs was the investment costs of the videoconferencing equipment and network which were assumed to have a lifetime of 5 years (3% annuity factor). The fixed costs also included the maintenance and rental cost of the ISDN lines. Since the videoconferencing equipment is also used for other purposes, 30% of the fixed cost were assigned to the Department of Psychiatry and 60% to primary care and these were calculated as the costs of the patient care planning negotiation.

The variable costs of videoconferencing included one and a half hour of wage costs for the participants (a physician and a specialised nurse at the department of psychiatry, a physician, a specialised nurse and a social worker at the Kuusamo primary care unit). The average Finnish wages (in 1996) plus the social security fees were used as the cost estimates (Statistics Finland 1997). The travelling costs of the staff were assumed to be zero in the videoconferencing alternative due to the short distances to the videoconferencing studios. In the conventional negotiation alternative primary care personnel have to travel to Oulu, which is 220 km from Kuusamo, and they lost about 6 working hours for travelling.

Technology

Most of the connections from the Department of Psychiatry utilised 3 ISDN lines. The mobile videoconferencing equipment (Videra VCS H.320 Roll' about) consisted of a video codec, which transforms an analog image into a digital one and vice versa, a controllable camera and audio unit, a direction unit, a microphone, a monitor, equipment to prevent echo in sound and 1-3 ISDN lines. The capacity of the codec and the quality of the image and sound is better the more ISDN lines are used (Mielonen et al, 1998, Telepsychiatry 1998).

Results

In our case the conventional negotiations cost twice as much as the videoconferencing alternative. Most of the primary care personnel would have been unable to participate in conventional negotiations at Oulu University Hospital due to travel time needed. The most important reasons for choosing videoconferencing were the reduction of the need for travelling by the participants, and the time used for the negotiation and the ease of having the negotiation (Table 1). Of the respondents, 90% were satisfied with the quality of the communication via videoconferencing.

	Personnel (n=76)	Relatives (n=11)	Patients (n=11)
Difficulty to arrange the journey	53	50	23
Ease of having a negotiation	83	83	85
Decrease of travelling	85	100	69
Decrease of travelling time	91	92	77
Reducation of expenes	84	92	54

Table 1: Percentages of reasons for choosing videoconferencing for the next negotiation by different participant groups (N=98)

Conclusion

Patient care planning negotiations via videoconferencing was cost-saving compared to conventional practice in the long run. The participants were satisfied with the quality of the interaction in videoconferencing and it is hence a feasible method.

Videoconferencing offers much more information to the participants than does a telephone conference and it is suitable for interactive communication of various kinds. Our rough cost estimates have also shown that videoconferencing with PC-based equipment is economic in telepsychiatry between primary and special-care units, even with a relatively low level of utilisation (about once every two weeks), if the distances are long and the costs of the lost working time are high. There was some resistance towards starting videoconferencing in the daily practice.

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Personalised software application compensating memory disorders

by Jaana Leikas, Juha Pärkkä and Petteri Jämsä

Abstract

The future TASC system - a stationary memory support system and an array of software modules - will be a pioneer in a new, virtually unexploited market that is expected to grow with the increasing elderly population. The system reminds the user of important events, e.g. taking medicine. The user is also able to make a phone call by touching on a photograph of the receiver and to browse through the photographs in the album by touching on the screen.

Memory disorders

Dementia is a common disorder in those of advanced age, posing a significant public health problem. According to WHO estimates there are about 8 million moderately or severely demented people in Europe. As the mean duration of life increases, more and more people will suffer from dementia. Around the year 2010 the estimated number of demented people, e.g., in Finland will increase by 20,000. Thus, the need for care as well as the expense of care will increase remarkably in the future.

The prevalence of dementia (the proportion of the population with the disease at a specific point in time), doubles with every five year increase in age for populations over 65 (Jorm 1987). Thus five per cent of those over 65 and approximately 20 per cent of those over 80 will suffer from dementia (Terry & Kattzman 1983).

People with dementia gradually lose their memory and their understanding. They become confused and frustrated as they cannot do things they used to do, gradually they become less able to look after themselves and have to rely on others to help.

With the help of new technology it is possible to create a home environment that is safe and prevents hazard situations. In addition to safety issues the newest research and development projects also concentrate on technology that would maintain well-being, help cope with life and organise the inner chaos of a person with memory disorders.

In most cases it requires training and learning to use new technology. We often think that a person with memory disorders is not able to learn new skills because

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of the deterioration of their cognitive abilities. Human functionality and activity is, however, based on subjective and personal experience and the lived life. Where people with memory disorders are concerned these inner factors have a much more significant role than the external ones. For example, in a situation where a person feels themselves threatened and helpless the sensitivity to signals that could increase feelings of safety are much stronger than for other impulses. These signals have significant emotional power and they should be exploited when designing new technology for people with memory disorders.

Many people with even severe dementia manage in their homes with the assistance of their relatives. The best situation from the person's point of view is when relatives living in the same household can constantly help and oversee the person. According to studies (Leikas et al 1996) safety concerns are commonly the biggest problem preventing a someone from living alone. Often the children of the person try to take care of them and this takes a great deal of effort and requires special arrangements. The relatives complain of worrying about the continuous uncertainty over possible attacks of illness; the person hurting themselves; going out at an inconvenient time or in improper clothing; fire hazards; forgetting to take medication, etc. The concern over the person not managing themselves causes a lot of unnecessary work. Some relatives may visit the person frequently during the day to make sure that everything is alright, some check on the situation by phoning the person several times a day, even though the information obtained by phone is often scant. These acts - however well-meaning they may sound - may disturb the daily life of the person with memory disorders and increase their anxiety. It is often the worry and the psychological stress of the relatives that creates pressure for transferring the person into institutionalised care, even though they could still be able to manage at home.

One cannot exaggerate the importance of living at home for people with memory disorders. The home has a special atmosphere: the familiar furniture and the order of furniture as well as the sequence of daily activities all play an important role: one follows the daily routines in a familiar environment despite the loss of memory. Compared to this, moving to a new environment may create chaos: nothing is on its usual place and everything is different.

One of the biggest problems when living alone and suffering from memory loss is how to remember to take medication. One doesn't remember to take it on time even though it is placed visibly on the table and organised in dosages. Sometimes you take too many pills, because you cannot remember that you have taken today's dose already.

Such a person may easily forget to eat. Because they don't feel hunger they don't remember to eat although lunch has been put in the refrigerator and all they have to do is to cook it in the microwave oven. Using different household machines gets more and more difficult: they forget the stove is on, the water tap running, or try to cook lunch in a plastic cup. As dementia gets worse they may start to wander. This could be highly dangerous, especially in the Northern countries where the winter is cold. They may go out at night, dressed only in a night gown, and not remember to take the keys.

Technology supports living at home

There are many emergency alarm systems already on the market but a person with memory disorders does not necessarily benefit from them. To use an alarm system the person needs to be able to behave adequately in a dangerous situation and to be able to call help either by using the phone or by using a wrist band device or other system. Mentally disordered people need technical solutions that will automatically react in risky situations by raising the alarm on behalf on the person. Since we already have experience of alarm systems functioning reliably for elderly people it would be rational to further develop this equipment so that it would also be suitable for needs of people with dementia.

Developing telematics applications that cover both telephone based alarms and computer technology is one way to approach the problems of people with dementia (people with slight memory disorders). In the TASC project (illustrated further in this paper) a system that covers both an alarm system and a computer has been developed. The system reports on hazard situations at home using a mobile network, both to the person with demintia and to a predetermined receiver of the calls. It is possible to connect different sensors or detectors to the system. The sensors or detectors will inform the system of different actions at home, such as fire hazards or falls. With sensors like these it is even possible to get information on sudden changes in the person's physical condition.

EMFi (Electro Mechanical Film) is a foil-like and flexible plastic material with a permanent electric charge. When exposed to a mechanical or acoustic force, this electric film generates a voltage, thus functioning as a sensor. EMFi can be used under a floor as an access monitoring sensor. EMFi floor consists of an EMFi sheet installed under the ordinary flooring. This sheet of film acts as a sensor recording footsteps and other movement. Applications of EMFi floor include patient monitoring. This is especially useful for monitoring nursing home patients suffering from dementia.

The newest solution in the area of personal safety can be found from the Global Positioning System (GPS). With this equipment it is possible to get one's own co-ordinates on a map with the help of the satellite signals. So far one has to be able to use the GPS navigator but it is envisioned that in the near future GPS, together with a mobile phone, could also function as a technical aid for a person with memory disorders. Then it would be possible to send the co-ordinates of the person to, for example, a carer's mobile phone.

"Cooker-Safe" is electric equipment attached to an ordinary electric stove. The equipment includes a timer and the stove becomes hot only within a certain time limit that has been set in the timer. This time limit remains until it is adjusted again. The stove can be equipped with a sensor attached on the wall above the stove and the sensor detects the temperature over the stove, when this is too hot it automatically switches the stove off. This kind of safety equipment is suitable for people with memory disorders because the already learned way of using the stove remains the same: one has to set the timer only once when the equipment is installed.

There is also electrically operated medicine dosage equipment where it is possible to set the week, days and the time of the day. The equipment sounds an alarm when it is time to take medication. This is not yet suitable for a person with severe memory disorders, however, the dosage equipment can be attached to a telephone that gives an alarm call to a certain telephone number if the person has forgotten to take the medicine. In neither case can one can guarantee that the pills have really been swallowed.

Software applications compensating slight memory disorders

The objective of TASC project, partly funded by the European Union, is to develop a memory support system with an array of software modules for people with cognitive disabilities. In Finland we concentrate on user interfaces for people with memory disorders in order to support home care and independent living. With support from the TASC system, people with a cognitive disability can achieve increased independence, increased self-assurance and improved social contacts. It is assumed that the TASC system can reduce the need for help from others with daily activities and thus lead to reduced dependency on personnel, friends and relatives, increased quality of life as well as reduced costs for assistance and institutional care.

The partners of the TASC project are: VTT Information Technology (Finland), Pikosystems/Prosthetic Foundation (Finland), The Swedish Handicap Institute (Sweden), Center of Rehabilitation Engineering (Sweden), SINTEF (Norway), Cognitive Rehabilitation Unit Sunnas Hospital (Norway), Danish Centre for Technical Aids for Rehabilitation and Education (Denmark), Royal Society for Mentally Handicapped Children and Adults, MENCAP (UK), Interactive Multimedia Technology Ltd (Ireland), Queen Margaret Collage (Scotland) and Advanced Medical Technology Ltd (UK).

The system works by reminding individuals about daily activities and providing assistance to complete routine tasks. These daily activities include 'must do's' like taking medicine. The reminders can be simple cues like 'take your pills' or a complex sequence to prompt the user through catching a bus or getting dressed. Plus there is a built in telecom service to allow individuals to contact relatives and friends. The user can to make a phone call by touching on a photograph of the receiver and to browse through the photographs in the album by touching on the screen. The TASC system has also the potential to be linked to sensors and appliances in the home.

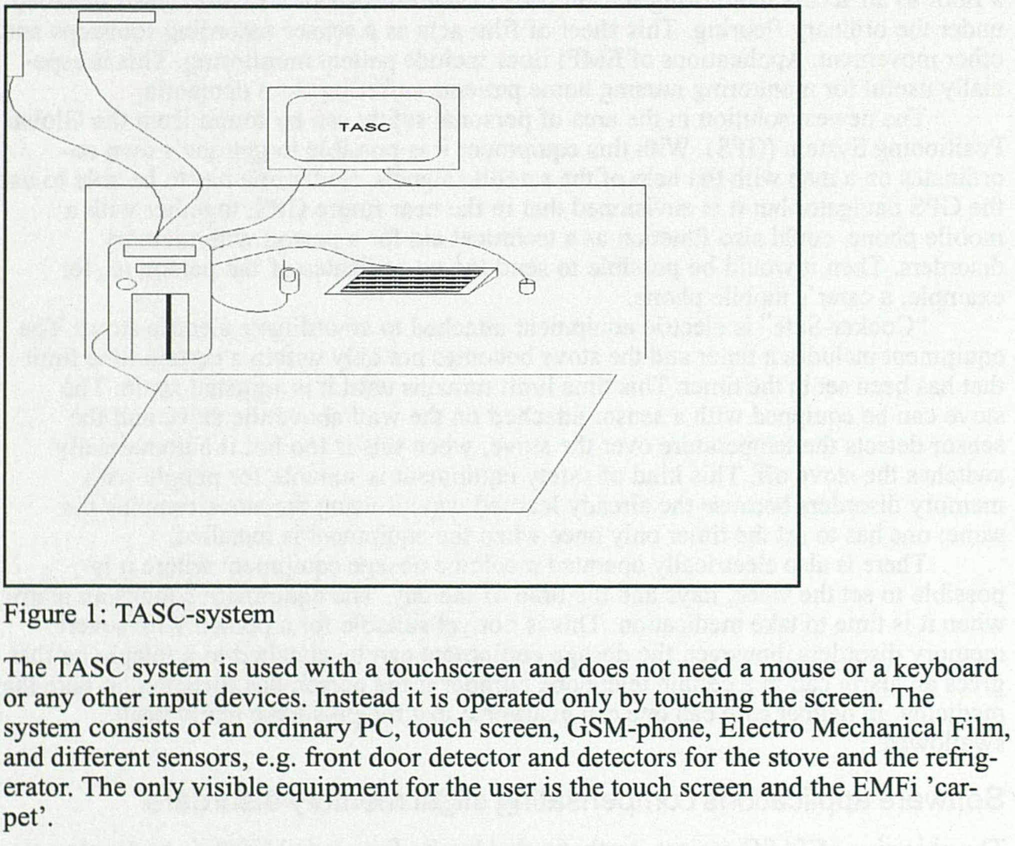

Figure 1: TASC-system

The TASC system is used with a touchscreen and does not need a mouse or a keyboard or any other input devices. Instead it is operated only by touching the screen. The system consists of an ordinary PC, touch screen, GSM-phone, Electro Mechanical Film, and different sensors, e.g. front door detector and detectors for the stove and the refrigerator. The only visible equipment for the user is the touch screen and the EMFi 'carpet'.

The system focuses on four core areas:

- Planning and time management
- Communication
- Environment supervision
- Information provision

Different modules have been developed to give support in these areas. The system runs on standard computers to keep the costs down. The modules are implemented with Java components in an architecture that facilitates future development and extension of the system.

1. *The Planner* functions as a reality board - it supports the user by keeping track of time, duration and details of activity. It provides a reminder when it's time to do a specific activity such as taking medicine, have lunch or watch the news. The user or a carer can schedule and reschedule activities while the system keeps track of the details. There is a large clock and a calendar on the screen. The clock tells you the time along with the date, the week day and time of the day , e.g." July 13th, Tuesday, afternoon". This 'reality board' always remains as the main screen when there is no other activity carried on at the same time. It helps in orienting the time in every section of the day. The calendar shows the date, the time and the activity that is scheduled on this specific time. It reminds you when it is time to carry out this activity. The reminder can be given in different forms: as a picture, photograph, sound or voice.

2. The most important communication service in TASC system is support for telephone calling. *Communicator* enables the user to make and receive phone calls via the system. The calls are made simply by touching on the photograph of the person on a touch screen. It is also possible to install an explanation behind the photograph, e.g.: "I am your grandson Matti, if you like to call me touch the green button". When receiving a phone call the photo of the caller is shown on the screen. Thus, one can communicate with the caller via a microphone and a loudspeaker and at the same time see the photograph of the caller.

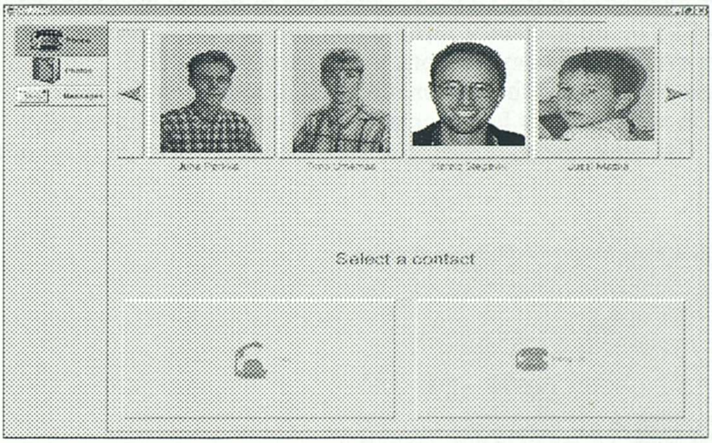

Figure 2: A phone call is made by touching a photograph

3. *Supervisor* processes information from sensors and with instructions configured by the user or the carer carries out appropriate actions. The *Supervisor* module processes the information that comes from the sensors. Taking into account input from several sensors it decides when it is time for an alarm. Several different types of sensors can be attached to the system to monitor a number of aspects in relation to the user's personal safety such as fire hazards or activity/passivity detection. The sensors in the refrigerator door and the front door react on opening and closing the door. The main purpose of these detectors is to inhibit the person from leaving during the night or leaving without keys, as well as reminding them to eat. A sensor in the stove reacts if the stove is overheated. All these sensors can give an alarm on the screen in different

forms: as text, picture, photograph, sound or voice. Most importantly, an SOS message as an alarm call is sent at the same time to a mobile phone of the relative, carer or a service centre.

To be certain that the person has noticed the alarm message on the screen an 'OK' button is one of the basic elements in the software programs. However, it cannot be assumed that a person with poor memory is able to push or touch on this button. When the message is given on screen the role of the EMFi carpet is to ensure that it has been noticed. This is done by detecting a step on the carpet on the floor in front of the screen and assumes that the message has therefore been seen. Although this EMFi solution is a prototype it is of great importance to people who are not able to use the 'OK' button to accept the commands of the computer.

4. *Information Provider* presents information in a simple format. The Information Provider encapsulates all the facilities to retrieve and represent miscellaneous information items for the user. Personal photographs and favourite music can be stored in the system with explanatory texts and sounds. This information can be browsed using the album interface of the TASC system. The photographs are a way to reminiscence and at the same time motivate use of the touch screen. They help a person orientate to the photographs with the help of text or voice that can be found behind the photo by touching on it. As an example, behind a photograph of a house can be found the text: "This is the house that we lived in during 1932-1966". By touching on photographs of people it is possible to get information on who they are, where they work, and so on. It is also possible to listen to a spoken message from this person. The album can also be used as a juke box. By touching on a picture of a favourite singer the person can listen to a favourite song and follow the words on the screen at the same time.

There are two user interfaces in the TASC system. One is for the user and the other for the person who fills in the necessary information such as texts, photos and voices containing data on events of the day, persons to call, and so on. TASC offers a simple interface for the user who fills in the information that is needed in the system. This user can be the person with memory loss themselves as long as they have only slight memory disorders. The most likely user of this interface is, however, a carer or a relative of the person.

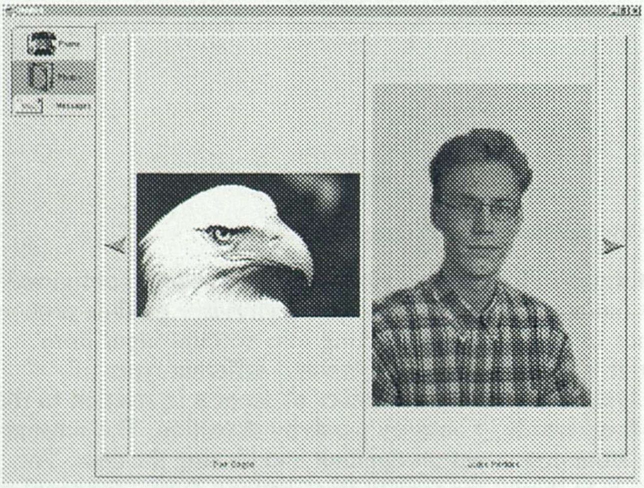

Figure 3: The album can be studied by touching on the screen

User-centred design

People who develop new technology should have continuing co-operation with the potential users of the new devices. The development should be carried out in the context and practice of user-centred design methodology. It is essential to bring the views and opinions of the users to the development process in order to enable a usable and functional outcome of the system, no matter who the user is; an elderly or disabled citizen or an occasional user. Within the principles of the user-centred design methodology the first outline of the product should be examined in the light of user requirements and user needs. The whole of the development work should be an iterative process where the primary and secondary users, developers and researchers actively co-operate.

Flexibility in respect to the individual user has been a key issue in the TASC development process. The modules can be configured to fit the individual needs of the user. For example, all information in the system can be presented by text, pictures, symbols and sound. The designers have adopted a ‘design for all’ approach. This approach was greatly influenced by the advice and help given by a User Advisory Group set up for the TASC system, including people from all the user groups, experts, professionals and carers. Also, as a result of the User Advisory Group being spread throughout Europe, it meant important cultural/local differences incorporated into the TASC product.

In TASC within the ‘user requirements definition process’ common needs of users with cognitive disabilities were identified, analysed and evaluated. Methods for knowledge elicitation in connection with people with cognitive disabilities were developed. The assessment procedures form a general framework for gaining more specific knowledge about user activities and the degree and type of intervention or support needed by people with cognitive disabilities to successfully carry out their present activities and activities that they wish to carry out in the future. The assessment procedures will be used and evaluated in the course of the project. The knowledge elicited from the assessment procedures will serve both to develop knowledge about users and user needs and to assess the need of, and determine preferences for the TASC product.

A framework for the introduction of assistive technology to the TASC target groups was developed. The framework covers aspects from awareness of product, set-up and instruction, to support and maintenance. The emphasis was on the project needs for user trials in the verification, and on gaining practical experiences with the procedures. Eventually in the project this will lead to procedures that are based on practical experience and which have been verified.

Functional specifications based on user requirements for cognitive assistive technology and software modules were developed, allowing flexibility and adaptivity to the user requirements definitions. The system will be evaluated at five sites (Denmark, Finland, Norway, UK, Sweden). In Finland the evaluation will concentrate on people with memory disorders.

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Computer based interventions for assisting people who have suffered disabling trauma

by Bryan Williams, D. Ramanee Peiris, Peter Gregor, Norman Alm, Susan Cumming, Gillian Flockhart and Marjory Groundwater

Abstract

An interaction with a computer can be designed to be smoothly flowing and pleasant, but free of any emotion or moral judgement. In this paper we report three case study projects where computer-based interactions were developed to be used in situations where people have suffered a disabling trauma. The interviews took place at a rape crisis centre, an alcohol counselling centre and in the management of post-critical-incident stress for emergency workers.

Introduction

Computers can give users a private environment where they can, in their own time, request or provide personal information about difficult subjects. In such situations, computer-conducted interviews have been found often to be easier for the interviewee than a face-to-face dialogue with another person. There is no embarrassment for the user and no bias on the part of the interviewer or information provider.

Slack and van Cura (1968) reported that gynaecological patients preferred the computer as the 'interviewer' on personal matters, and Sanders et al. (1994) found that the majority of patients interviewed about their HIV risk behaviours preferred to use the computer to disclose sensitive information. Interviewees have been observed to be more open about personal or sensitive topics when answering the computer. For example, Chun et al. (1976), interviewing epilepsy sufferers, found that urinary incontinence was reported by 10% of interviewees to the computer, but never to a physician. Duffy and Waterton (1984), surveying alcohol consumption, noted 33% higher levels of consumption reported to the computer interviewer than face-to-face. Locke et al. (1992) found interviewees reported more HIV risk factors to the computer than face-to-face.

Such findings may arise from the fact that users know the computer is only a machine, which cannot be shocked or upset, and will not form a negative view of them, as a human might. When discussing sensitive topics, therefore, the inhuman nature of a computer seems in some ways to be an advantage.

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It can be difficult to prove that people are in fact more honest when being interviewed by computer. However, in reporting a study at an alcohol clinic, Lucas et al. (1977) commented, "There seems to be no reason why patients would exaggerate their alcohol consumption to the computer, whereas psychological literature abounds with examples of interpersonal behaviour being modified towards social acceptability." Their patients revealed 30% higher consumption to a computer interview than to psychiatrists. Lapham et al. (1991) examined prenatal risks and found that more interviewees admitted drug use to a computer than to a written questionnaire. Answers to the computer interview were confirmed subsequently by urine testing.

Computers can be programmed to keep no record of the dialogue which has taken place; so users can request information or explore feelings without the possibility of anyone else having oversight of them. In some cases, computers have acted in what could be considered a therapeutic capacity. For example, Schneider et al. (1990) demonstrated that their computer-based smoking cessation program had a 24% success rate. Gregor & Newell (1994) reported that with school pupils who had to imagine being caught truanting almost all (15/16) reported that it would be easier to be truthful to a computer in a real situation, even if they knew that someone responsible would be discussing their responses later. It may be, therefore, that computers can be used in a direct therapeutic role, helping users to cope separately with the acts of disclosure before moving on to confront their consequence.

A further possibility is that computers could be used as a tool by people who have been through a difficult experience to help them come to terms with it, alongside the help being offered by counselling and other methods. In this paper three pilot projects are reported; each deals with a situation in which the client has experienced some kind of *disabling trauma* which they find difficult to deal with, but which they need to deal with themselves further, before being in a position to get further help. In each case a computer-based intervention was developed and is described together with the preliminary results of its application

Rape crisis centre

A rape crisis centre was the setting for an experiment in the computer-aided visualisation and processing of emotions. The centre is an agency, mainly staffed by volunteer workers, offering help, advice and counselling to woman survivors of rape and domestic violence, of all ages. It has been found that many of the women using the centre have great difficulty identifying and expressing their emotions. A major part of the support work focuses on this. The workers use a variety of techniques to help the women, including drawing, diary keeping and free writing. The centre also supplies a range of information leaflets.

A computer-based intervention was proposed, in particular to help women communicate their feelings in a manner which enhanced empowerment, a key aim of the centre's work. Such a system needed to be easy to use and not interfere with the activity itself. Its design could not make any assumptions about a woman's previous computer experience. It was hoped that the system would provide a safe environment for expression , and also that a sense of achievement from mastering and using the system might raise the user's self esteem.

A prototype system was developed to augment the centre's information gathering and self-expression activities via a desktop computer, to be used before, during or after a face-to-face meeting with a worker. It included an information database, a writing area for diary keeping and a work area for examining feelings. The prototype was developed in conjunction with centre workers and computing professionals with women's support experience.

The writing area took the form of a personal diary that the user could access from any part of the program. It allowed the women to type whatever they wanted, and included a timer, to prompt after a specified length of time. Workers have previously found that intense emotions are often raised during free writing, and they find it helpful to tend to set a time limit for this activity. The work area allowed women to write down their current feelings and graphically represent them - changing fonts, size and colour of the text. After exploring the individual feelings the woman could choose to file and 'keep', or 'destroy' the feeling in several different ways. The information database presented information provided in some of the paper leaflets, including details on dealing with the police and court procedures.

A formative evaluation was conducted, using the model of co-operative evaluation (Monk et al., 1993).The main problem encountered was that the prototype had been constructed with simple presentation software and the limitations this imposed interfered with the ability of subjects to judge the usefulness of several key aspects of the program because it was hard to 'imagine' how these might function when properly programmed. Nonetheless, the seven subjects were positive about the general program content and balance, although it was felt that too much factual information had been presented in places. Particularly well received, both by project workers and by service users, were the graphics representations designed to assist users with handling their strong feelings. It came as something of a revelation that such powerful but hard-to-reach emotions could be represented and dealt with in this tangible manner. One woman, for example, described her previous experience of anger as "...a ball which was deep rooted within her stomach, but was too far down to reach..." She felt that using the program had, for the first time, given her a way of understanding and getting to grips with this negative aspect of her past experience.

Project workers universally considered that such a program would add usefully to the techniques already employed in their work and there was thought to be great value in the idea of using it on successive occasions so as to compare changing experience over time. One subject stressed the value of being able to look at information in her own time and without the risk of being discovered doing so by close relatives or friends. To summarise, the most positive features of the prototype emerged as: the level of control over process it gave to the user (the presence of an 'Exit' button was seen as exemplifying this); the 'trust' that seemed to build up between the user and the program/programmer; and the ability to visualise and represent strong feelings graphically within a therapeutic context. Preliminary results, therefore, were encouraging and certainly positive enough to warrant investment in further programming and program development.

Critical incident stress management

The emergency services (for example, fire service, police, paramedical and casualty staff) often deal with traumatic and difficult circumstances, from major disasters such as a train crash to an individual event, such as the death of a child. Work-related stress among emergency workers arising from such incidents is a major problem, and debriefing techniques are already in place to help individuals cope with such situations. Workers are given opportunities to express their feelings about the incident, talk about their own performance, and also the management of a situation. This can prevent long term psychological problems which could hamper their future work performance.

However, those involved sometimes feel it necessary to take more time discuss an incident beyond that allocated for them at work. It may be impossible, for reasons of confidentiality, to talk to their family or friends about an event, or they may not want to tell anyone the exact details of an horrific incident for fear of causing upset.

Nevertheless, it is beneficial for people to disclose their feelings by talking or writing about the incident, or talking about disabling symptoms, such as flashbacks or insomnia.

A web site was developed to assist emergency workers to explore their feelings following a critical incident. The site was developed to contain information about stress and coping mechanisms, and news articles about other critical incidents. It also included an interactive self-risk assessment tool and a structured conversational-type computer interview to aid disclosure. The aim of the web site was not to replace the need to talk to other people; rather its role was to supplement support mechanisms already in place, and meet the short term urgent needs of an individual.

Evaluations during the site's development were carried out with police officers and both ward and casualty nursing staff. The users provided feedback on the site's content, its design and navigation methods, and their suggestions were incorporated into the next version. They viewed the aims of the project favourably, with typical comments being :

> *It would be useful for new emergency workers, dealing with something for the first time.*
>
> *Most of the time you are trained to cope with trauma. Sometimes you are more able to cope than others. This would be useful for those times when you are not coping well.*

This user added that staff frequently knew that the reason for not coping was temporary or that it was specific to a type of event, and did not feel that it was necessary to seek help at work.

Some evaluators suggested users should be allowed to reflect on the information they had provided with summaries produced; others preferred not to see information once it had been entered. They wanted to be able to comment on the performance of others as well as themselves, with the option of anonymity. Medical personnel wanted to be given the choice to record information, but the police officers felt that recording would breach confidentiality and trust.

The web site was designed to be informative, supportive, interactive and confidential - currently no data is stored. Future developments could include options for confidentiality and anonymity or identification, and the provision of a chat room where users could chat to others who have been involved in similar, or even the same critical incidents.

The aim of the whole site is to help people who have been involved in a critical incident to reflect on this experience privately, possibly with a view to sorting out their feelings before speaking to either colleagues or a counsellor. The reflective experience might be expected to help the user to decide on whether they believed further assistance was needed. The ability it affords users to move between a range of pages offering different kinds of interaction is designed to provide a richly textured interactive experience, with the opportunity to learn from information pages and to reflect through typing in answers to questions about recent traumatic experiences in the interview page.

Tayside Council on Alcohol

Tayside Council on Alcohol (TCA) provides a counselling service to people whose life is affected by alcohol misuse. Each person who attends the agency is treated as an individual and no-one is persuaded to accept a particular perspective on alcohol problems. TCA see counselling as a process which helps give someone an opportunity to explore, discover and clarify ways of living more resourcefully. The counsellors help people to understand the causes of their problems and to identify appropriate solutions; they also help people work towards a greater feeling of well being. Clients decide whether they want to abstain or to control their drinking and for those who plan to control their drinking, counsellors try to provide education on safe drinking levels. Counsellors find great difficulty in obtaining accurate drinking consumption figures for both men and women. People with alcohol problems often feel intense guilt and shame (Plant, 1997) and partly because of this they under report their drinking levels. When a client attends for a face-to-face counselling session for the first time, counsellors can be hindered by not having any background information about the client, but it may not appropriate for a counsellor to start by asking a rapid series of questions. Clients tend to start talking about a particular problem they have, and counsellors must pick up information about the client as they go along. The counsellor and client may build up a close relationship over several sessions, but important personal details may still not be known. Information gathering difficulties can work both ways. Experience suggests that the initial complaint may mask other worries which clients would like to disclose if they think the counsellor has the time to listen.

For successful counselling, it is essential that counsellors try to build an open, trusting relationship with the client. This can lead some counsellors not to ask sensitive questions because they fear negative reaction from the client. Sensitive topics such as serious debt or abuse for example, may lie at the root of a drink problem.

A computer-based interview was designed for TCA to use as an initial contact interview tool, prior to the first counselling session. The interview aimed to gather complete information about client's drinking patterns, together with relevant health and social issues. It produced printouts for both the client and counsellor to use in the subsequent counselling sessions, and possibly retain for comparison purposes in later sessions. The software was designed to be easy to use, with multiple choice answers selected using mouse input, and very few questions which required typed answers. As the interview progressed the questions asked were tailored to the individual and based on their previous answers.

Workers and clients from TCA were involved in the design of the interview and evaluations. Feedback from clients was positive; contrary to initial concern that clients would not be computer literate, many clients had been on a computer course, sent either by the Job Centre, the Social Work Department or the prison where they were serving a sentence. Two examples are reported here, with clients' names changed to preserve confidentiality.

John was an unemployed man from Dundee who was attending his first appointment. Before the computer interview John reported that he had not been drinking for six weeks, and when he saw the screen saying he would be asked about his drinking habits, he asked what he should do as he was "off the drink now". The researcher informed him that he would be able to enter that he had not drunk anything. The first question in the drinking section asked when the client's took his last drink, and John entered "yesterday" He went on to complete the program and it transpired that during the past seven days he had drunk 98 units of alcohol. This is apparently much less than six weeks ago before he "came off the drink".

After the computer interview John was interested in seeing the printout. As TCA try to help clients take control of their lives and encourage them to make their own decisions, it was decided that clients could choose to have their own copy. John seemed relieved that the computer would inform the counsellor of his problems, which would avoid the need to spend an hour 'confessing'.

Frank was a 27 year old man in prison - such clients usually deny any alcohol problems, but most have a good relationship with the TCA staff, and were therefore happy to take the computer interview. The researcher and counsellor sat in the same room as the clients; they could not see the computer screen, but were aware of the clients' progress by the comments they made aloud. Frank answered "Yes" to "Have you had someone trying to make you do something sexual when you did not want to?" As he pressed the key he had said "Yes, all the time." He had also answered "Yes" to having someone deliberately and repeatedly trying to upset him. When answering these two questions he had spent longer than on other questions. In subsequent discussions it emerged that before the computer interview Frank had never applied the label 'abuse' to what had happened to him, and the act of doing this had a powerful emotional effect on him. The abuse may well have been part of the reason for his drinking and the attitude change which the interview brought about could form the focus for subsequent counselling sessions.

Previous work with computer interviews for people with alcohol problems has established their usefulness in obtaining more truthful estimates of current drinking patterns, and this was confirmed in our study. What may be a direction worth pursuing is making a more directed use of the ability of a computer interview to provide a non-stressful and relatively unthreatening way to explore very personal issues, such as the root causes of problem drinking.

Conclusions and future work

The three projects described here exploit the findings of this group and other researchers, that people are often more comfortable answering difficult questions and exploring personal feelings when their 'conversation partner' is a computer rather than another person. Specifically this can be the case when individuals have suffered some sort of trauma which has left them withdrawn and unable to talk about it or their reaction to it. The tools developed all sought to be part of a process which helps to empower users to take control of their lives, gave them a chance to explore their situation, and get help from the appropriate people.

Work is now needed to take these projects further. The work on alcohol abuse is being continued and now includes a longer term study on subsequent drinking behaviour. The rape crisis centre work on visualisation of feelings is also being carried further. Other application areas where such work might prove useful include child abuse, mental illness, and drug-related issues.

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Social service provision supported by technology

Monitoring child care in adverse circumstances

by Andy Bilson

Abstract

In many Central and Eastern European countries there is a deepening crisis with increasing numbers of children ending in institutional care. This paper proposes a methodology for empowering managers and practitioners to plan and monitor changes in welfare services for children. This will enable those providing services to develop effective local child care strategies.

Introduction

A key area of concern for children in Central and Eastern Europe is the welfare of children who are looked after by the state. The proportion of children in state care varies between countries from, for example 0.42% in Moldova to 1.7% or almost 1 in every 50 children in Romania (DPC 1998)[1]. Evidence from UNICEF's MONEE project suggests that despite efforts to improve the services to divert children from entering state care that there was an increase in children in care between 1989 and 1996 in most of these countries. Whilst in many cases the conditions of children looked after by the state have improved there are still major problems and many very young children are still cared for in large institutions. In their introduction to the fourth monitoring report Gáspár Fajth and Judith Harwin (UNICEF 1997 p. vii) state:

> *Nowhere is the gulf between economic progress and social impoverishment clearer than in the worsening position of a group of children whose voice to the outside world is still rarely heard: children in public care.*

Whilst considerable efforts are being made to change this situation a key problem is how to ensure that these

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[1] These figures are from the MONEE project which can be obtained from the TransMONEE Database at http://Eurochild.gla.ac.uk/documents/monee and from the Romanian Government's report "Child Rights Protection System Reform Strategy Implementation Program (1998 - 2001)". It should be noted that the way that the number of children in state care is calculated may vary between countries. However, even allowing for these variations, the figures show that there are a significant proportion of children cared for by the state.

efforts are effective. This paper considers an approach being piloted in Romania by the Department for Child Protection with consultancy from the Centre for Europe's Children. It is suggested that it is possible to provide help to countries whose welfare services are in transition by developing a monitoring system which can be used to focus efforts effectively, evaluate the success of different approaches and provide evidence of what works at the local level. In particular this approach is intended to empower and enable those managing services without adding impossible burdens in data collection or the need for expensive upgrades to computer systems and software.

Monitoring reforms

There is much evidence that attempted reforms of systems of welfare and control can have unpredictable outcomes. It is therefore important to have feedback on the effects of the efforts to bring about change. This is not only the case in Central and Eastern Europe but has also been found in countries where there is not the same stress of massive social and economic upheaval.

A major issue in managing change in welfare systems is that changes frequently have unintended consequences which often totally undermine the original objectives. For example, one well documented effect of attempts to reform system is 'net-widening'. Net-widening occurs where there is an attempt to replace a service by setting up new services (for example when foster care is being promoted to replace residential care). What often happens is that, rather than replacing the original service, the new service becomes an addition and the 'net' of welfare services is thrown more widely.

Whilst there is no simple solution for dealing with unintended consequences a key issue in minimising their effects is for the welfare system to be properly monitored. If system monitoring is taking place those who are undertaking reform will be able to identify what problems occur in the local system and design reforms which can address them. They can also keep track of the effects of the changes they make and identify problems early.

Whilst many services collect information, for example, on the numbers of children in state care, their age, reason for entry and other demographic details this does not provide a basis for effective monitoring. Research has shown that such monitoring needs to cover the careers of children through the care system and to collect information on key decision points in that career, such as the decision to take the child into care (Bilson and Ross, 1999). This paper is aimed at providing a framework for developing tools for systems monitoring which can be applied in situations of adversity such as those currently found in Central and Eastern.

Systems monitoring is most effective where it has been used at a local level to gather key information and where it forms part of a strategy to empower managers and practitioners. This means that the information must be meaningful to the users, simple to collect and easily provide feedback on the services for which they are responsible. Because of the limited resources available for monitoring in Central and Eastern Europe it must also be capable of being undertaken without major hardware purchases and require the minimum of staff time to operate it. Finally if the system is to be used in different countries and for different purposes it must be adaptable to the different legal and practice systems.

In order to achieve this the Centre for Europe's Children is undertaking a pilot project in Romania sponsored by the European Children's Trust and working closely with the Romanian Government's Department for Child Protection. This pilot is aimed at developing a methodology for systems monitoring which the Centre for Europe's Children will make available through its on-line services. It will also seek to build a network of correspondents who will be able to provide advice and guidance on the use of systems approaches.

This paper outlines the current work on the pilot project in Romania. The project builds upon the European Children's Trust's extensive experience of developing services in adverse circumstances and its established presence in Romania. The pilot is develop the tool working with staff from the Romanian State agencies and work in Romania is carried out in partnership with CRIPS, a Romanian consultancy service.

Developing a systems approach

There are a number of steps needed to develop a systems approach. These will be described here as if they are a sequential but in the real world they overlap or the order may change. The starting point for the systems approach is to map the system. This is followed by designing and developing monitoring systems and the third area is developing staff resources to use the system. In discussing these areas the paper will use examples drawn from the Romanian system. These examples will have to be adapted for application in any particular legal environment in which the approach is used.

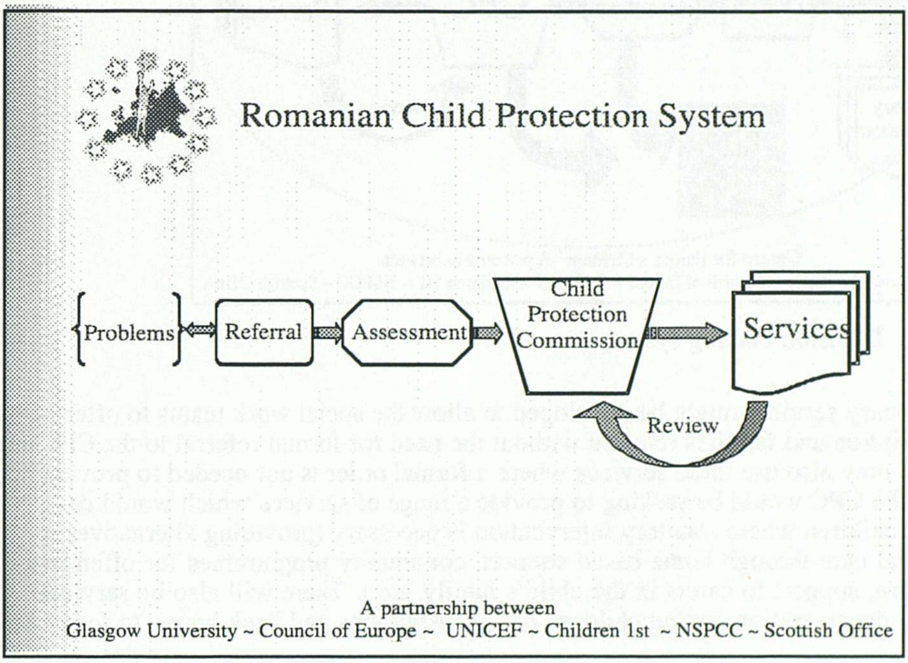


Figure 1. Legislative Systems

Mapping the system

In order to start to think about a systems approach it is important to start by mapping the system. To do this it is helpful to draw a map or maps of the decision making systems that lead children to enter care. Figure 1 shows the new system being introduced in Romania following the implementation of the Emergency Ordinance on Children in Need (DPC 1997) and the DPC's Strategy (DPC 1998) which devolved decision making and provision concerning children in care to local authorities which set up Child Protection Commissions (CPC). This figure gives the legislative framework and figure 2 overlays this with possible points of intervention at which services might be applied to divert children from deeper entry into the formal system. Thus it shows that primary preventive services might be applied to problems at the local or community level. In the

Romanian context these might include free contraception and sex education to prevent abandonment of children due to unwanted pregnancies through to free school meals and advice on social security to prevent entry to care due to poverty and neglect.

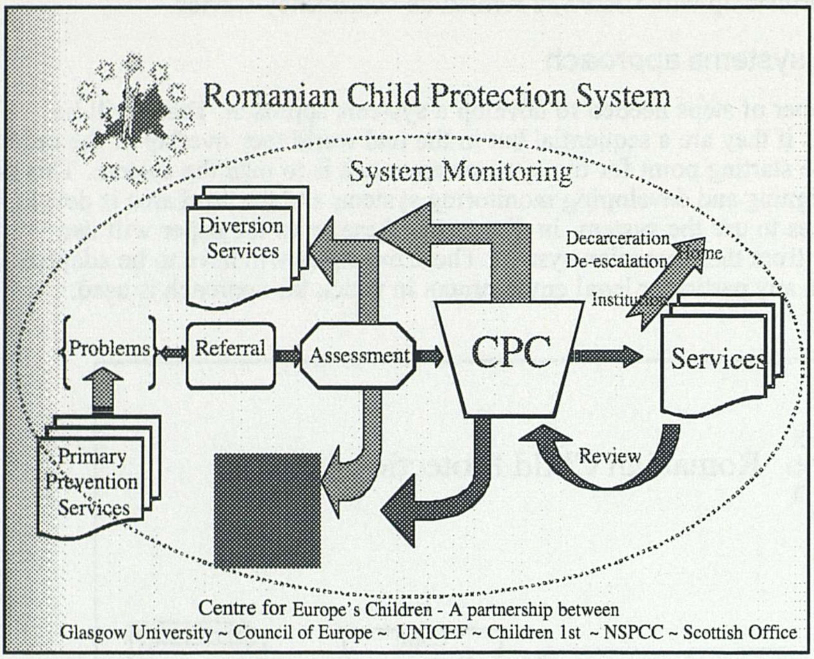


Figure 2. Decision making system

Diversionary services might be developed to allow the social work teams to offer help to those children and families referred without the need for formal referral to the CPC and the CPC may also use these services where a formal order is not needed to provide help. Finally the CPC would be seeking to provide a range of services which would de-escalate children where statutory intervention is necessary (providing alternatives to residential care through home based support, community programmes for offenders, foster care, support to carers in the child's family, etc.). There will also be services aimed at decarceration getting children out of institutions and back home, to foster care, etc.

This conceptual map is important as it helps to highlight the different points of intervention and identifies the decision making system itself as a target for change. In developing a systems approach in work in the UK and Australia as well as Romania the author has been struck by how difficult it is for managers and practitioners to visualise the system in which they work and drawing even such a simple diagram can be a step towards identifying key strategies and intervention points.

Designing and developing the monitoring system

This section will consider issues in designing and developing monitoring systems. In Romania it is proposed that a series of pilots will be developed before the system is implemented nationally in the early months of next year. This very tight timescale is necessary because of the urgency of the problems, the need for accurate information on the services and the need to plan interventions more effectively.

In modelling the information system around the model of the decision making system mapped in figure 2, it is important to ensure that it will be able to produce information on service careers and also on the decision making process. In addition tothe information on the decision making system there will be information relating to the child and family, and to services. However despite this broad aim it is important to ensure that the minimum of information is captured. Frequently information systems fail because of the desire to be overly comprehensive in the hope that the system can collect all relevant information. The author has found that it is better to think of the systems as being able to help to form better questions than to give comprehensive answers. It is also the case that information systems frequently demand information which is excessive, unobtainable in day to day practice or ill defined and of little use. For example in Scotland the national system requires information on the position in the family (1st child, 2nd child etc.) of the child entering care. There is no definition, so it is not clear whether to count only full or half-siblings, adopted siblings, children of a cohabitation, siblings living in another household and so on. In addition it is unclear about how such information might be analysed or its use and it is not surprising that there are no published reports on this element of the data collection. Figure 3 gives brief details of data items likely to be included in the Romanian system

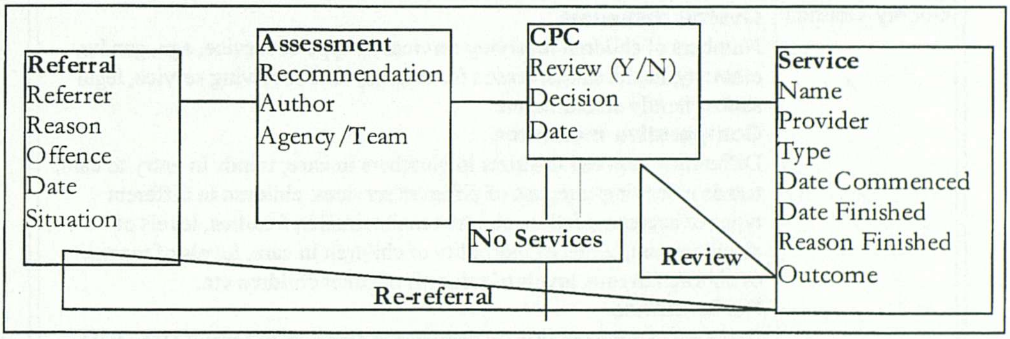


Figure 3. Data items for Romanian information system

The aim is to provide an information system capable of monitoring performance of the services. In Romania it will monitor the CPC's decision making and the role of the child preotection teams. The system will thus allow managers to identify good practice as well as where problems are occurring. For example even where good services are being provided net-widening may occur because of increased referral; unfocussed assessment and recommendations to the CPC or through decision making of the CPC itself. The monitoring system will allow the location of the problem to be identified and targeted. In particular the system will be able to provide a wide range a range of measures of performance whilst being sufficiently focused to minimise the number of data capture items.

The monitoring system will provide a massive range of information which can be used to monitor the operation of the child protection system. This information will be available at *all* the different levels of the system. Thus patterns will be available at the national level showing overall trends but also providing comparative information on and between County Councils; at County Council level information will be available on the operation of Judets and local strategies; whilst information will also be available down to the level of individual services or children's homes. Table 1 gives an indication of the possible range of information and reports that will be available. Because of the ability to combine information in a number of different ways this table necessarily underestimates the possible reports. It is important to note that this extensive range of measures will be available from such a limited data set.

Level	Reports / Measures
National	**Overall measures** Numbers of children receiving services by type of service, age, gender, ethnicity, health status, reason for referral; time receiving service, legal status, family situation, County Council, etc. **Comparative measures** Differences between County Councils in numbers in care, trends in entry to care, trends in leaving care, use of different services, children in different types of accommodation, children maintained in families, levels of abandonment, levels of morbidity of children in care, levels of mortality of children in care, levels of referrals of street children etc. **Performance Measures** Decrease in numbers in care; decrease in numbers in former large state run institutions; increase in numbers accommodated in families and smaller institutions; increase in use of community based services; decrease in abandonment of children; a match between use of alternatives and community based programmes and reductions in care and street children population (i.e. age, gender, ethnicity, reason for referral, etc.)
County Council	**Overall measures** Numbers of children receiving services by type of service, age, gender, ethnicity, health status, reason for referral; time receiving service, legal status, family situation, etc. **Comparative measures** Difference between Districts in Numbers in care, trends in entry to care, trends in leaving care, use of different services, children in different types of accommodation, children maintained in families, levels of abandonment, levels of morbidity of children in care, levels of mortality of children in care, levels of referrals of street children etc. **Performance** Decrease in numbers in care; decrease in numbers in former large state run institutions; increase in numbers accommodated in families and smaller institutions; increase in use of community based services; decrease in abandonment of children; a match between use of alternatives and community based programmes and reductions in care and street children population
Child Protection Committees	**Overall measures** Number of children referred by outcome, recommendation, reason for referral, legal status, age, gender, ethnicity, health status, etc. **Performance measures** Proportion receiving institutional care; proportion of social work recommendations for alternatives followed; proportion of re-evaluation measures leading to care/educative/internment measures

Table 1 Reports and measures available at different levels (continued on next page)

In Care Monitoring	**Entry to Care** Numbers entering by age; gender; ethnicity; establishment; County Council; District; health status; Family situation; disability; Reason/ circumstances on entry; legal status, referrer etc. **Leaving Care** Numbers leaving by age, gender, ethnicity, time in care, destination (e.g. family, independence, institution, death); legislation; disability, health status, educational achievement **Population** Census by age, gender, reason for entry, time in care, time in placement, type of placement, decision of last review, family situation (i.e. orphan, single parent etc), family contact, legal status, disability, health status, county council etc. **Performance indicators for children in care** These would be available for all children in care, county council, or individual institutions Increase in family contact; increase in numbers with identities registered; increase in numbers attending ordinary schools; decrease in death rates, decrease in poor health status (e.g. AIDS/HIV, Hepatitis etc.); Increase in rate of leaving; decrease in length of stay; increase in return to family/parents, foster care, adoption; decrease in leaving to other institutions
Services aimed at reducing entry to care	**Measures** Numbers referred by age etc compared with rates of entry for the target group. This will provide information on the match between those receiving alternatives and the target population for the service Reduction in entry to care in target population Level of service provision - comparison between reduction in entry and numbers receiving service Success of alternative - Level of entry to care of children who have previously received alternative Career measures - length of use of alternative and subsequent use of services
Services aimed at taking children from institutions	**Measures** Increase in numbers leaving care early (i.e. at younger age, not to other institutions etc.) who have received service Success rate - proportion leaving early that have received service Targeting - proportion of children in institutions falling in target group (i.e. age gender reason for entry, type of institutional care, particular problem focus etc.) that receive service Career measures - level of breakdown, re-entry to institutions, etc. Outcome measures - level of children leaving the service to go to adoption, family, independent living
Services for street children	**Measures** Decrease in referrals of children living on the streets where services available and used Targeting - fall in number of street children in target group similar to numbers receiving services Career Measures - level of breakdown, placement in institutions, offences etc. of those receiving service Outcome Measures - number of children receiving service who return to family, or non-institutional care

Hardware and software issues

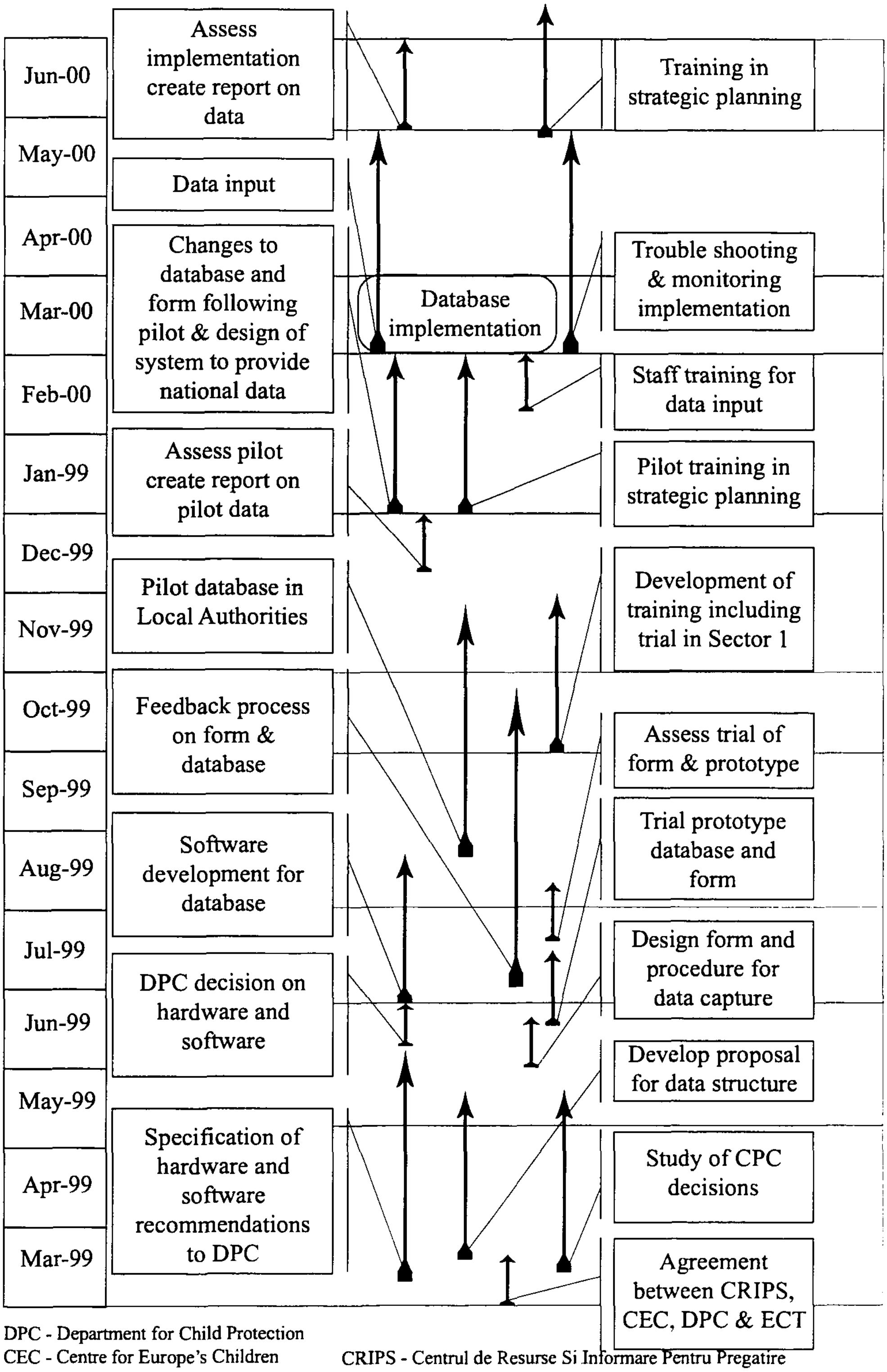
The level of available technology will vary between the different countries of Central and Eastern Europe and this paper is written on the basis that it would be possible to carry out this approach using stand alone PC's running MS DOS. It is not the sophistication of the hardware that is important but rather the ability for software to be available which will allow easy analysis by staff not used to data analysis – social workers and front line managers. The Centre for Europe's Children will provide through its web site copies of *Mandate*, a database programme for data analysis and capture that can be used to analyse information by staff with a minimum of training. However, it is also important that in the short to medium term the system should be able to migrate to a Windows or networked Windows environment and that in the longer term there may be a need to move to a network environment either nationally or at least locally. The following discusion is aimed at provision in a Windows environment (although the aim is to make it available on machines running windows 3.x or above and including 486 based processors) with a view in the longer term that any system should be easily transferred to a network environment. However, in Romania it is likely that funding will be available from PHARE to move directly to a networked system.

Where Windows systems are available the database files for the monitoring system can be produced in *Microsoft Access* database format. Using *Microsoft Access* itself to enter and analyse data would mean limiting use to Pentium processor based computers with large amounts of memory and would also mean considerable software costs if Access is not already licensed. *Access* databases offer ease of creation and amendment; the availability of some record locking making them usable on local networks; better security; and a clear upgrade path to *Microsoft SQL Server* for any extension to larger multi-user systems. To allow a range of current equipment to be used it is proposed that the Centre for Europe's Children will provide a data analysis programme, *XTAB* on the same basis as *Mandate* - namely that copyright is solely owned by the author but a free license will be given for its use in monitoring child protection programmes in Central and Eastern Europe. A simple *Visual Basic* front end can easily be written to capture data. Adding this to an analysis package with small code and the ability to run on both 16 bit and 32 bit operating systems will reduce costs; extend the range of machines that the system will be able to run on; be quick to load and to operate; and provide a very user friendly interface. It will also be possible for the system to be used on local networks where these are available. This approach of using *Access* databases and *Visual Basic* data entry and analysis would allow a progressive move from these systems to a network environment particularly with the ease of translation of *Access* to *SQL Server* offered by *Microsoft Office 2000.*

Training key staff in strategic use of information

All of the above is aimed at producing a tool to empower practitioners and managers to take on a systems approach to their work. Systems monitoring is most effective where it is used at a local level to inform policy and practice.This means that the information must be meaningful to users, simple to collect and easily provide feedback on the services for which they are responsible. Staff will need training in the use of information to identify strengths and weaknesses in current policy and practice and the development of strategic responses based upon the information. In Romania it is proposed that a training programme will be made available to key managerial staff in County Councils. This will use a constructivist approach to the training (Bilson 1995) providing exercises in the analysis of the 'live' data from the monitoring system. The training will be aimed at helping managers to focus their interventions on the system as

Figure 4: Implementation diagram



DPC - Department for Child Protection
CEC - Centre for Europe's Children
ECT - European Children's Trust

CRIPS - Centrul de Resurse Si Informare Pentru Pregatire Profesiuni Sociale a whole through identifying patterns and challenging the beliefs that lead to repetitive and unhelpful patterns of service (Bilson and Ross 1999). In Romania a series of 2-day courses for 10 to 16 people are planned, to be held in each of the 8 County Councils. The goals of the programme will be:

(a) Provide a theoretical framework for systems monitoring and strategic planning
(b) Provide skills and knowledge of data analysis
(c) Provide skills in the strategic use of information
(d) Provide experience of presentation of data to achieve change

The programme will involve staff in working in small groups to analyse and develop strategies using information drawn from the monitoring system on children in care. The Centre for Europe's Children is developing a training team to lead these courses. Whilst much of the paper has focused on the development of the information system it is the staff training and consultation that is crucial to the successful implementation of a systems approach. Figure 4 shows the planned implementation programme with training and consultation built into the process.

Conclusion

The worsening economic circumstances and legacy of institutionally biased policies in many Central and Eastern European countries has led to a deepening crisis with increasing numbers of children ending in institutional care. This paper lays out a programme for the development of a methodology for empowering managers and practitioners to plan and monitor changes in services for children in state care in Central and Eastern Europe. This will provide a resource which will enable those directly involved in providing services to develop effective local strategies to prevent unnecessary entry into institutions with the long term problems this entails. Once developed the tool and support necessary to use it will be made available through the Centre for Europe's Children's on-line services.

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The Community Services Network (CSN): creating an integrated service delivery network - the Baltimore open systems laboratory model

by Gregory A. Stosuy and Joseph P. Eaglin

Abstract

The CSN laboratory approach model has created the opportunity for system planners and system users to more effectively understand the dynamics and requirements of integrating service delivery and management information functions that were originally designed to operate as independent, isolated structures.

This model has led to the creation of an integrated service delivery network -'utility' - that directs and manages resources for enhanced coordination and delivery of health and human services.

Introduction

Problem:	Myriad services have been authorized at the federal and state level without creating either direction for them or the capacity to manage them as a system at the local level.
Solution:	Create an integrated service delivery network - a 'utility' - that directs and manages resources for enhanced coordination and delivery of health and human services. The utility operates as a point of delivery distribution system for the full range of service providers and administrators.

For the past nine years, Community Services Network, Inc. (CSN) has developed innovative approaches to 'process re-engineering' and electronic, multimedia tools that support delivery of *integrated* health and human services. By services we refer to all social, health, employment, education, housing and legal services, especially those services that are intended for persons that are dependent upon public programs. By multimedia tools we refer to scalable software and networking applications that support single point of intake, collaborative case management, cross-program tracking and reporting, and the interface and migration of legacy data bases.

The CSN open systems laboratory model intended for Baltimore, Maryland, was conceived as an interactive forum. It is a *collaboratory,* where state and local program administrators, community agency managers,

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and frontline workers come together with software designers, network planners, managers and systems integrators to review, test, refine and measure the potential impact and benefits of collaborative solutions. Meeting the needs of staff at all levels is a key determinant to successful implementation (Oyserman and Benbenishty, 1997; Moultrie, 1997). The CSN model allows for *iterative prototyping* and involves the constellation of people, processes and technology to define and implement a workable integrated system.

Integrated services and information systems are critical to the current demands for overhaul of public human services programs in the United States. They involve creation of linkages and new *infrastructure* between child welfare, family support and medical, mental and public health programs (Hile, 1998). Infrastructure defines connectivity between community support services for adults, the disabled and the aged, as well as juvenile and family justice systems and employment and training initiatives. These linkages are necessary to effectively implement reforms in state welfare programs, Medicaid managed care, child welfare information tracking systems (Oyserman and Benbenishty, 1997), and the coordination of adult and juvenile court systems.

The new infrastructure involves both collaborative processes and electronic connectivity between the disparate elements of the service delivery community. It includes both lateral and vertical information sharing to support collaborative case management across agencies, programs and services modalities. It uses advances in computing technology to formulate multi-agency care plans for an individual or family at the local level, and data base development for inter-departmental, program management and planning initiatives at the state level.

The CSN laboratory approach models this infrastructure and creates the opportunity for system planners and systems users to more effectively understand the dynamics and requirements of integrating service delivery and management information functions that were originally designed to operate as independent, isolated structures.

Development of integrated service delivery systems

Driving the demand for integrated service delivery are the requirements of program managers to balance user needs with available program resources. Therefore the laboratory model is built on 'real time' information systems that monitor the status of operational variables across many agencies, programs and funding streams. These variables include:

- Systematic monitoring of user needs
- Unit service delivery pricing and cost monitoring
- Uniform collaborative case management across city/county departments, community providers and commercial delivery systems
- Daily on-line assessment of program resource utilization
- Cross-program provider/client tracking
- Integrated data bases and reporting across agencies, services, populations and funding sources

Of equal importance is the need to facilitate the development of cross-program measures of service delivery *impact* on targeted user populations, by geographical areas and by provider configurations. There is also the need to create multi-program databases that allow for more accurate determinations of unduplicated counts of persons being served and more reliable estimates of the total amount of expenditures for each individual, family or groups of families in the service delivery system.

The laboratory model is based on the CSN approach to integrated service delivery. This involves three interrelated components:

1. *A Re-engineering Process* that facilitates and trains frontline workers, systems managers and program administrators to think and work as teams across agencies, programs and funding structures and to develop inter-agency *protocols* for sharing clients, data and resources. An important component of the process is to provide the necessary expertise to the frontline workers as well as meeting each agency's information needs at all levels (Oyserman and Benbenishty, 1997)
2. *A Multi-media Platform* consisting of a suite of software tools that support both desktop and database integration and allow for single-point of entry, collaborative case management and cross-agency/program ad hoc reporting and monitoring
3. *An Interoperable Network* that creates connectivity between provider agencies, local service departments and between local and state systems.

Figure 1 below illustrates the levels of systems development, where each successive level requires greater process, more complex software, and more robust network connectivity.

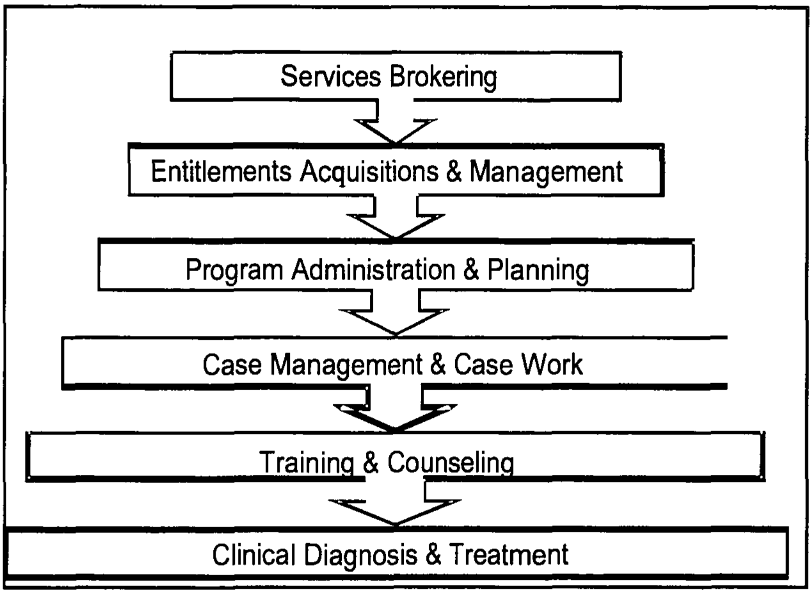

Figure 1. Levels of system development

The process

Creating integrated service delivery systems is a dynamic process that involves intensive efforts in inter-agency team building, adapting and developing collaborative technologies, and strategies for blending resources and sharing management responsibilities across programs and organizations. Figure 2 overleaf describes the dynamics of this process.

Team building is the cornerstone of integrated service delivery. The process creates interdisciplinary teams of intake and caseworkers; inter-agency teams of systems managers and support personnel, and cross-program policy and management teams of

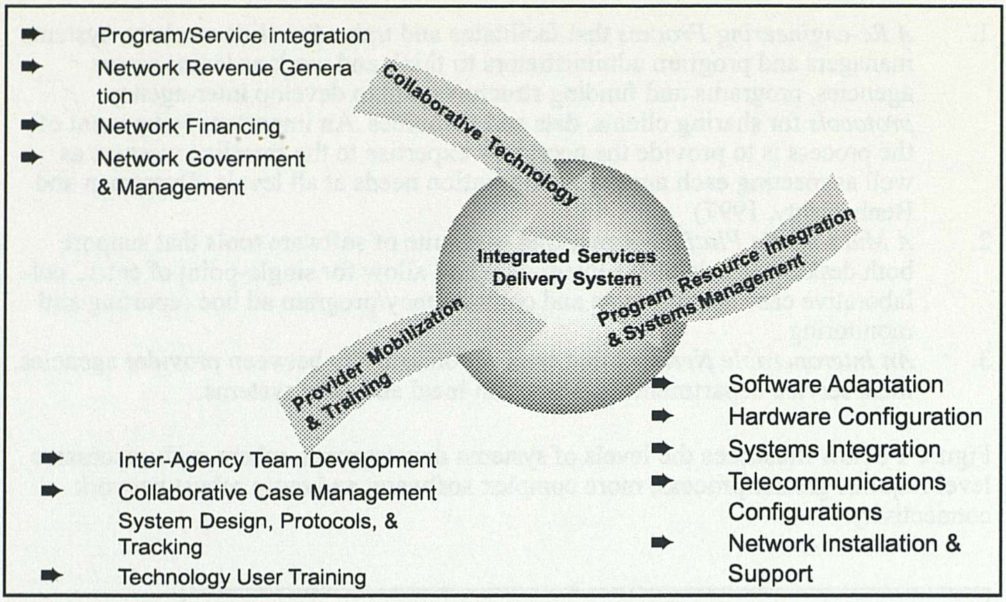

Figure 2. Dynamics of integrated services delivery system

administrators and program planners. The CSN laboratory model enables members of a case management team to co-ordinate across time and distance to assess a client's needs, develop an inter-agency case plan, and monitor and adjust the plan to ensure that proper care is provided. Inter-agency technology support teams develop integrated network configurations, share responsibilities for supporting the collaborative software, and provide help desk support to participating agencies. Monnickendam (1996) discusses the importance of system usability as a significant predictor of intended computer use by human service workers. Agency administrators form cross-program/department governance teams that manage the development and blending of resources to support the network and formulate policies for the day-to-day operation of the collaborative initiative. Figures 3 and 4 below illustrate collaborative, inter-agency teams.

Protocol development is an on-going function of the inter-agency teams. Protocols are the guidelines, the 'do's and don'ts' and road maps for how agencies are to conduct themselves on the collaborative network. Protocols determine access to the system, how data and case files may be shared, and how routine emergencies may be handled. They provide guidance in determining the balance of needs to resources, and the priority or order of service delivery for types of cases and target populations. They also provide directions for blending services and short cuts for expediting care across diverse agencies and operations.

Confidentiality and network security are also governed by inter-agency protocols created by the teams and enforced by the electronic data management system. These protocols center around authorization of how information and data may be shared on the network. They govern who may read, hear, enter and update data on client files andservice databases. They mirror the 'need to know' policies of the agencies and the wishes of the clients being served.

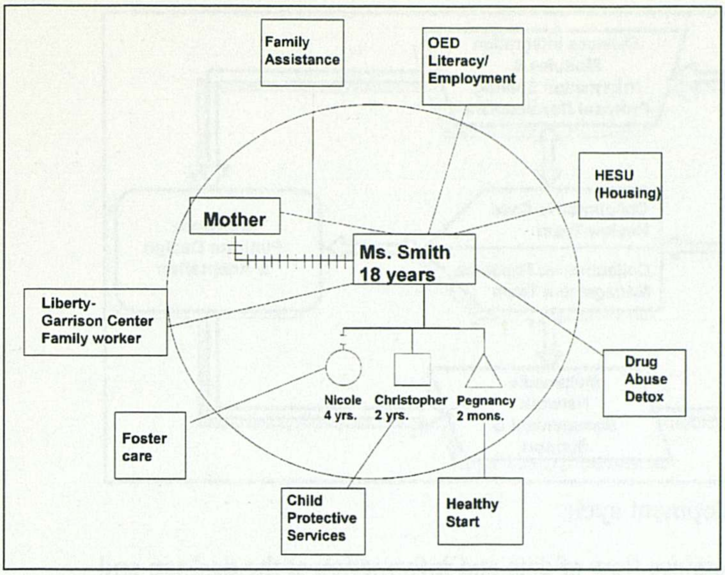

Figure 3. Collaborative case management team

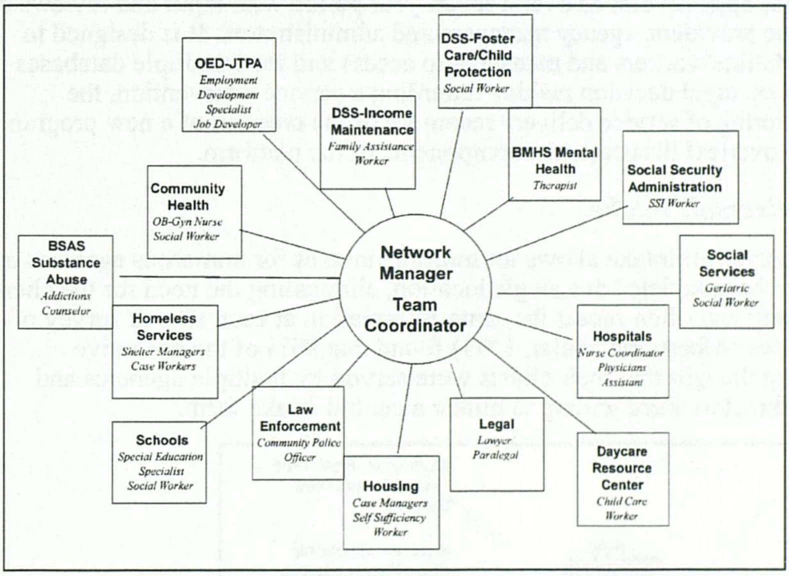

Figure 4. Interagency management team

Team building and protocol development are critical elements of the infrastructure of integrated service delivery systems and are the first steps in a continuous network development cycle. Collaborative teams formulate inter-agency protocols. These protocols inform the design and adaptation of the software platform, and the platform defines the functionality of the telecommunications network. The network operation is continually monitored and evaluated. This leads to the development or adjustment of protocols and the process repeats itself. Figure 5 depicts the network development cycle.

The CSN software platform

The CSN software platform consists of a series of data-sharing and communications

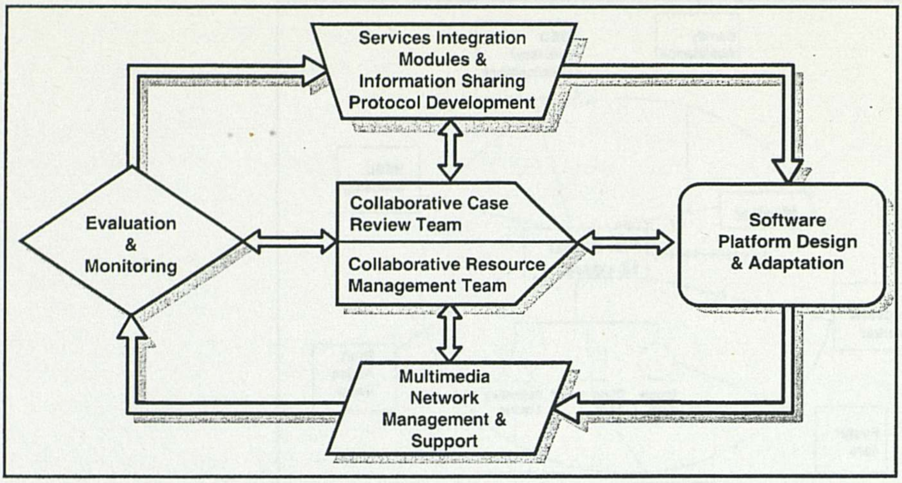

Figure 5. Network development cycle

tools that support the seamless flow of data and information at the desktop and databaselevels and across providers, service disciplines and programs. The cutting-edge suite of software has been developed over a seven-year period with input and reviews of thousands of service providers, agency managers and administrators. It is designed to enable teams of frontline workers and managers to access and feed multiple databases and conduct complex, rapid decision making regarding a service intervention, the utilization or monitoring of service delivery resources or the creation of a new program initiative. Figure 6 overleaf illustrates the components of the platform.

Single Point (Universal) Intake

The single point (universal) intake allows for multiple intakes for numerous agencies or service providers to be completed at a single location, eliminating the need for the client to go to every agency and often repeat the same information at each site. A survey of ocial service agencies (Albers and Millar, 1993) found that 95% of the executive directors responding thought that their clients were served by multiple agencies and that 76% of these directors were willing to utilize a central intake form.

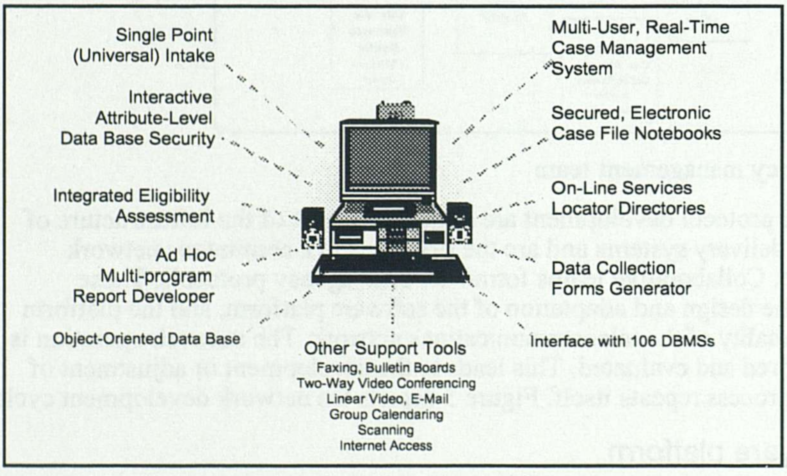

Figure 6. Community services network platform

Universal Intake is the critical tool for the single point of entry system. It enables case managers and data collection clerks to conduct intakes for multiple agencies from a single location. It also creates a common or collaborative database across agencies, service domains and funding streams. The CSN universal intake system is created within an object oriented software application and structured around a 'global data dictionary'[1], an electronic thesaurus and 'real-time' - live - database that interprets the differences in meaning and presentation (format) for all information elements used by each agency on the network. The intake system also uses a 'forms' generator and contains the electronic intake and case management forms for each agency. This enables one agency worker to complete the intake for their agency, then access another agency's form on which common intake information may be transferred automatically, subject to the client's approval. This automated data-sharing process can be repeated for as many agencies as necessary to meet the client's needs.

Referrals and *Tab Level Security* are sub-functions of the universal intake system that apply to introducing a client to another agency and sharing selected or entire portions of client information with that agency or multiple agencies. In a point and click process, the worker, with client consent, determines the tabs (categories) of information to be shared. The agency directors surveyed by Albers and Millar (1993) saw a breach of confidentiality as the most negative aspect of a centralized intake form. Only the information approved by the client for sharing will be transferred. This is non-repudiation, desktop control security, where the confidentiality agreements between clients and providers are designated at the point of intake and sustained at all times and at all places on the network.

The agency can also designate certain information that can never be shared and must be completely suppressed. These designations are made at the dictionary level in the agency's notebook of data elements. They are data level protocols that only the client or a change in an agency's guidelines can override. Consistent with the traditional referral process, release of information forms are maintained for each agency on the system, printed out, signed by the client, and scanned back into the system and attached to the client intake or case management file. To underscore desktop control, only the originating agency can change a data element. When agencies do not have access to certain information on a client upon referral, the system informs them accordingly unless all information on the client is suppressed. If access is necessary and approved by the client, the system designates the originating agency source. The release of information process may be conducted electronically and save the client considerable time, frustration and expense.

Collaborative Case Management consists of shared case management files and forms that may be viewed and updated on-line by an inter-agency team of case workers. The use of video conferencing for remote intake interviews, case meetings and case reviews is intended to reduce costs and enhance the capacity of agencies to create collaborative service plans. The case management tools are real-time information systems that are updated with each event in a case implementation. All case managers on a team will be enabled to track the progress of treatment or care plans as clients move from one agency to another.

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[1] The global data dictionary is the central CSN proprietary software. It is an objects oriented technology invention that functions between the intake process and the resulting database. Data elements on agency forms may be changed or moved around and new data elements may be added without having to reprogram the database. This is a major cost saving innovation in the area of information systems for health and human services. It is also the technical basis for granular level security, multi-program databases, and rapid referrals. It allows for flexibility and creativity in integrating programs and services and creates the 'co-ordinating intelligence' that is necessary for such efforts.

Legacy Interface and Report Generation will be provided through use of the Visual Enterprise Information System (VEIS) a product developed by Promia, Incorporated of San Francisco. Like the CSN application, the VEIS is an objects oriented system and accommodates security controls initiated at the desktop. It has the capacity to generate both ad hoc and fixed reports and allows for easy reporting to and extraction from a large number of standard databases without programming. The interfaces allow for the seamless flow of data from the desktop to the large state and county systems or large databases of local private institutions.

The network

The CSN network is an *Intranet* – a type of limited access Internet or private network using public transport lines. In the early stages the primary mode of connectivity was ISDN – integrated switched digital network, allowing for 128 Kbs of bandwidth that is necessary to support simultaneous transmission of data, voice and video. The ISDN solution also was considerably more affordable than dedicated lines or fibre, and allowed for connectivity of numerous community-based agencies who operate on limited or fixed budgets. Ultimately the network was a mixed architecture of ISDN, dedicated lines and fibre backbone of state agencies. See Figure 7 overleaf.

Currently there are many options for deploying CSN networks. These include DSL and ATM switches that allow for five times the bandwidth and speed of ISDN and often for lower prices. Seamless connectivity between community agencies, county and city agencies, state departments and large commercial institutions such as hospitals create a transactional platform where the business of health and human services is conducted. The application of granular, attribute level security enables these networks to operate as a large, single agency or the ‘virtual settlement house’, where all the services were located in one big room.

The laboratory

The Baltimore Laboratory was intended to create an opportunity to conceive of the myriad of services and operations as a single system of care, where there is the potential of co-ordinated care and vertical integrated case management. The types of agencies involved in the Baltimore network planning project included:

- The East Baltimore Mental Health Partnership
- The Baltimore Department of Social Services
- Medical Services of the Circuit Court of Baltimore
- Lombard Middle School
- The Family League of Baltimore
- Families Involved Together (Family Counseling)
- Baltimore Substance Abuse Center
- Catholic Charities (Multi-Purpose Center)
- Child Advocacy Network (Child Protection)
- Baltimore Headstart
- Baltimore Regional Office of Juvenile Justice
- The Housing Authority of Baltimore
- The Gate Youth Employment Center
- The Johns Hopkins East Baltimore Medical Center

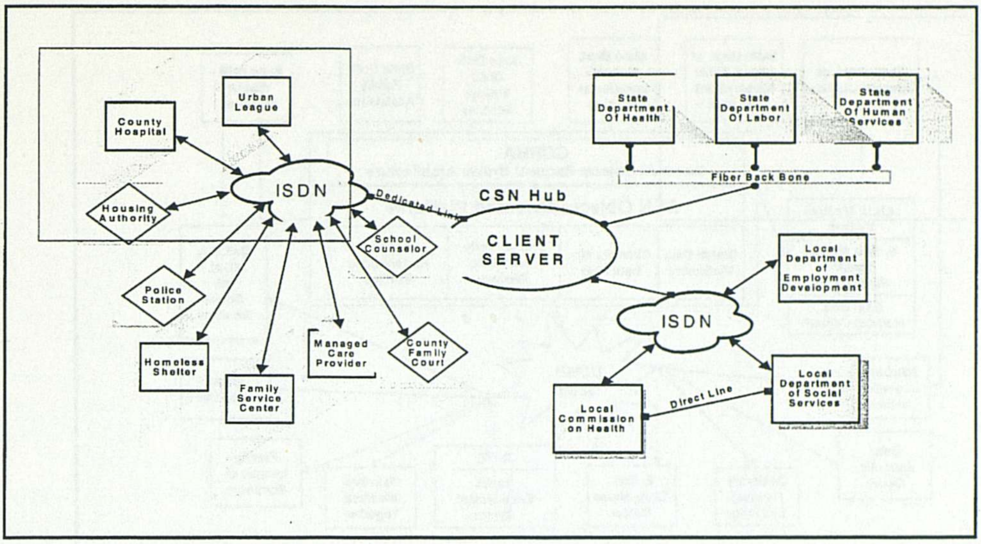

Figure 3: The network - an intranet

The laboratory model allows these agencies to have seamless data flow and connectivity to the large agencies that include:

- The State Department of Juvenile Justice
- The State Department of Labor and Employment
- The State Department of Health and Mental Hygiene
- The State Department of Human Resources :
    - Child Welfare Services
    - Family Assistance
    - Social Services

This level of connectivity allows for tracking clients, individuals and families across agencies, departments, funding streams and service modalities. It allows for the creation of integrated data files on individuals and families that can provide a clearer picture of the range and types of persons seeking assistance or being served by the collective array of programs. Electronic case files allow for analysis of variation in treatment approaches and profiles across the various care systems and quantifiable measures of the extent or variation of care for target populations or service groups. As the global data dictionary allows for the interpretation of data element definitions across legacy databases, new analytical databases can be generated to create the basis for integrated unit pricing of services, comparative treatment or intervention measures and service delivery impact measures.

Integrated network benefits

The benefits of integrated networks are realized in three areas: service delivery itself, service administration, and program planning/policy formulation. Enhanced outcomes and use of resources result in *efficiencies*, measured in reduced time and cost, and *effectiveness* with respect to individual client services and broader strategies for health and human service delivery.

Service delivery benefits in integrated service networks are expected to demonstrate:

- Significant reduction in the cost of client intakes
- Significant reduction in the cost of client referrals
- Significant reduction in the cost of collaborative case management, and

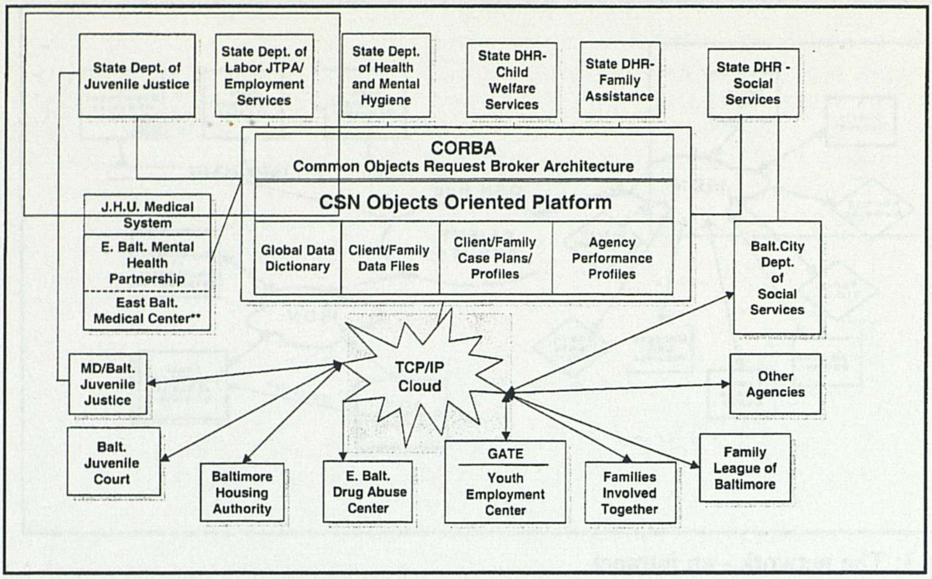

Figure 8. Open systems/services integration laboratory

- Significant reduction in the time and cost of moving a client from one level of dependency to a lesser level of dependency.

Administration benefits are projected to include:
- Significant reduction of cost in determining the status of clients
- Enabling the creation of unit pricing for types of agencies, types of services or service clusters, and types of clients
- Significant reduction in the time and cost of producing periodic and ad-hoc reports by, and
- Significant reduction in the time and cost of authorizing benefits.

Benefits of program planning and program evaluation include:
- More accurate forecasting of service delivery costs for types of clients, types of service, and types of agencies
- More accurate budget planning for multi-agency program implementation, and
- More accurate measurement of the impact of service delivery and program policies across agencies and funding streams.

An initial evaluation model designed to test these assumptions is being applied to each network deployed by CSN, adapted to the particular needs and priorities of each community. Documentation of time and cost savings and of priority network functions becomes the basis for network expansion across agencies and across domain areas.

The Internet as an implementation business model

Across the first 14 communities in which CSN conducted network planning, one challenge consistently proved the most difficult: how to fund a data-sharing network across numerous agencies which had little if any experience in funding projects together? Dollars up front for an untested, capital intensive product are hard enough to procure. But when those funds must come from multiple agencies with fixed budgets, the task becomes even more daunting. We broke out the $6 million total development budget into four six-month phases, each phase fundable upon successful completion of the one before. Still, the $1.5 million downpayment was too much.

Emergence of the Internet in the last three years led CSN to a new business model. Instead of capitalizing the cost of a network that the users would jointly own, why not present the users with a service for which they would pay a monthly fee? Why not have CSN and its network partners develop and own the network, which would provide the range of content, functionality, and connectivity specified by the users? Like AOL or other Internet Service Providers, CSN would charge a monthly fee for its service, finance network development costs through its own investment sources, and recover its costs over the first year or two of expanded network operations.

With this Internet implementation model, agencies do not have to procure scarce capital dollars for which they have not budgeted. Instead, they allocate available operating funds to pay for a service – an enhanced communications system – that quickly begins to save them time and money.

There is another reason why the system is a zero-budget proposition for many communities. In such communities, deregulation of the telephone industry means competition and lower cost for the enhanced, high bandwidth service for voice and data required of integrated networks. These savings in monthly line charges may prove to equal or exceed the CSN user fee, making operation of the integrated network cost-neutral from the outset.

Background

Origins: 1990: CSN began as a nonprofit initiative to explore strategies for the delivery of integrated services, a cooperative effort involving Howard University, Baylor College of Medicine, Rice University, and a coalition of health and human services providers in the District of Columbia. The federal government provided funding to explore both the process of collaborative case management and the deployment of cutting-edge technology in health and human services delivery.

Development: 1992: To expand federal support, the project was moved to Macro International, Inc., a government services consulting firm. Development contract funding came from the Public Health Service, Social Security Administration, Administration for Children and Families, and National Institute of Standards and Technology (Advanced Technology Program). The process for network planning was further developed and refined through contracts with 14 cities and counties across the country. The software platform was further developed and refined through a cooperative agreement with Lawrence Livermore National Laboratories.

Formation of CSN, Inc. 1996: Having completed the proof of concept and prototype development, Macro International spun off CSN in April, 1996 as an independent company. To initiate network deployment, CSN developed strategic alliances with its first network partners, including Lockheed Martin Federal Systems for systems integration, Nortel for telecommunications support, and DNS Technologies (now Promia) for software development and support. Successful beta-testing of the software occurred in a 2-month network demonstration in Reno, Nevada, followed by network planning and negotiations in Baltimore and with the State of Maryland.

The present: Alliances with Newbridge Networks and Structus Technologies provide strong telecommunications capacity, leading to the Internet business implementation model.

Network demonstration sites:

- Network planning for the Masonic Charitable Foundation of Oklahoma introduces CSN to key State and private health care officials, now negotiating with CSN for a State-based pilot network focused on health care, managed Medicaid, and family support services.
- Larimer County (Fort Collins), Colorado approves 'sole source' agreement for a County-based demonstration network incorporating health, justice, and family service agencies.
- Pima County (Tucson), Arizona convenes all courts and justice agencies to commit to a demonstration network with a focus on justice and health.

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Seamless service chains in social welfare and healthcare information technology in Finland

by Sirpa Kuusisto-Niemi

Abstract

The development work in Finland is based on the National Strategy for utilising Information Technology in Social Welfare and Healthcare in Finland. It has produced several pilot projects around the country, the largest being the Satakunta Macro Pilot. Its goal is to develop a client oriented seamless environment, which crosses traditional organisational lines and boundaries. At the same time work is underway nationally on terminology. The idea of this work is to define common concepts in welfare services and healthcare, to be used for developing seamless service chains.

The welfare and healthcare service structure in Finland

The Finnish social security system is based on the the idea of Nordic welfare state. Its core features include broad coverage of social security, universal, equal public services for all and income transfer systems, a sufficient level of social security and the decentralisation of welfare service provision. The principle of the welfare state stresses universality as a means of preventing the exclusion of the individual and of creating equal opportunities for all. The social security objectives are, as far as possible, achieved by means of preventive work, social assistance and services. Finland's social security will continue to depend to a great extent on the public sector, supplemented by the developing and diversifying services of the private sector.

As a result of a large degree of autonomy with elected councils and taxation rights, municipalities shoulder the main responsibility of providing healthcare and welfare services and guaranteeing subsistence for people without means. Each municipality produces its own services or in cooperation with other municipalities, or purchases them on the private market. Municipalities are subsidised by the Government to cover their expenses. At present approximately 100,000 people are employed in municipal welfare services.

The Social Insurance Institution, a national insurance agency under parliamentary supervision, is funded mainly through insurance contributions from the insured and employers. The functions include, except for

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basic pension, various additional functions, e.g. allowances, not based on social insurance but funded through taxation. Earnings related employment pensions are paid by private insurance companies, but collected in taxation. Use of advanced computer technology is a cornerstone of SII's operations, with a huge computer centre, large mainframes and customised software.

The nationwide development and planning activities take place in the ministry of Social Affairs and Health. It sets the overall guidelines, but municipalities practice independent and locally adaptable welfare and healthcare policy within the framework of the legislation. The state policy in Finland is put into effect through the five provincial administrations. Provincial Boards have Departments of Social Affairs and Health, who supervise implementation of welfare and healthcare policy of the municipalities the Province territory.

The information technology development issues in Finland

Based on the European development in utilising Information Technology in society in 1994 the Government of Finland adopted the strategy called 'Finland to Information Society' which has now been revised twice. Information on this process can be found at website http://www.vn.fi/vn/english/index.htm

National Strategy for utilising information technology in social welfare and healthcare in Finland

Based on the tasks in the first national strategy the Ministry of Social Affairs and Health published its own corresponding strategy at 1996. The objectives of the strategy are:

- to create an information society for all
- to grade services to form integrated service chains
- to strengthen the municipality, the basic unit in the networking of social welfare and healthcare services
- to establish multidimensional data networks
- to improve the scope of the client and the individual
- to improve data protection and data security
- to further the integration and compatibility of information systems
- to ensure a competent, vigorous staff
- to make versatile use of of the available knowledge and know how
- to promote IT reseach and know how in social welfare and healthcare
- to reinforce the welfare cluster

The implementation of the strategy is a multidimensional networking process, that means development of cooperation on several levels: local, regional, national and European. The strategy was followed by two memoranda by the Ministry on seamless chains and data security. These memoranda list actions to implement the goals described above. These actions include education, suggestions for cooperation between several national level actors, cluster activities between authorities and enterprises and concrete projects. Some methods of implementing this strategy into practice are presented below.

Pilot projects

The use of information technology by municipalities was introduced in the 1960s. Over the last years Finland has witnessed the development of several regional and local partial solutions in the sphere of seamless welfare and healthcare services. These include, for example, referral and care feedback systems between primary and secondary healthcare levels, several telemedicine applications and Internet-based healthcare information systems for citizens (e.g. databases of care programs and quality manuals).

It is now possible to collect evidence on how information technology can be utilised in developing and implementing the welfare and healthcare services on the regional level. The Ministry of Social Affairs and Health is supporting projects which are specifically focused on seamless service chains. It has launched over 20 pilot projects, most of which have already been finished, but some are still in progress. Of those the most interesting from the viewpoint of welfare services are:

- The regional networking project between welfare services and health, named SONETTI, which started with the purpose of establishing a regional strategy on data management, whereby a database for a research and care programme could be devised to be used by various organisations in their client administration.
- The seamless service concept for health care, the PALKO Project, which will implement a process-based and client-centred data transfer model in healthcare. The goal is to remove boundaries between organisations by creating information services shared by various organisations and individuals. There is a tendency to shift the focal point of care away from institutions and to create proper working conditions for the personal physician system so that the dialogue between the patient and physician can be improved.
- The regional information system in welfare and health, the ASTERI project, which will enhance the regional residents' and clients′ access to data on the services. It will also intensify client guidance and counselling, improve the accessibility of the services and the clients' active participation. It will facilitate client contact and provide residents with an interactive channel and an opportunity to take part and have a say in these questions.

More information on these projects can be found on website
http://www.oskenet.fi/eike/e/introduction/index.html

The Satakunta Macro pilot project

The aim of the the umbrella project, the Satakunta Macro Pilot, is to utilise the results of local development efforts performed in different parts of Finland, and to combine these results into a country-wide project with the purpose of developing innovative working methods. Its goal is to develop a client oriented seamless environment, which crosses traditional organisational lines and boundaries. It is also an umbrella project in the sense that it involves both welfare services, healthcare (including pharmacies), plus local NGOs, social insurance institution, information technology enterprises and educational institutions.

The purpose of client-centred seamlessness is to reform the traditional organisation-centred operational procedures in welfare and healthcare and to improve the availability, standard and efficacy of these activities. The target is also to improve control of the total service system expenditure, thus making possible a raise the operational standard and efficiency. A major aim of the project is also to contribute to the improvement of data protection and security, due to the prospects and risks resulting from information technology solutions.

A constituent part of the structural change, which the welfare and healthcare system is presently undergoing, is support for independent living and management of daily chores at home. The Macro Pilot tests the practicability of systems and technological solutions related to independent living and home care. It also tests their integration into the whole of the welfare and healthcare system.

The Macro pilot is going to develop and test such information technology infrastructure and architecture which support a client-centred seamless care and service system. The developing and testing work also covers the connected information and telecommunication technologies,.information-technological solutions, and data networks with the connected value-added services. It will also create an operational model for organising the training required for utilising information technology. The pilot aims at the creation of solutions and products which might be utilised both nationally and internationally.

The Macro pilot includes efforts to develop secure solutions for information networks, smart card technological applications, solutions required for the co-ordination capabilities of network databases, and multimedia applications usable in welfare and healthcare.

This project's lifespan is 1998-2000, and it enables the opportunity for simultaneous testing of several information technologies and their solutions which support the implementation of the service chain. It is characteristic of the Finnish welfare and healthcare databases that client data are classified by organisation or by service provider. The best way to implement the total view of the client's service and care history, as required by the seamless service, is to use the client card as a key to enter national reference databases.

The client card has a crucial role in the macro pilot which performs testing to find out the type of client card needed, its operative qualities and required data contents. Results of the pilot will be used as a basis for evaluating the prospect of developing the citizen card further to include the functions of a client card of welfare and healthcare and social insurance.

The target is to combine the results of the above development efforts and the existing client databases in welfare and healthcare into one comprehensive system. This might serve as a basis for the creation of innovative Finnish enterprises and perhaps also of export products.

Welfare cluster

The welfare cluster activities started in 1995, and welfare cluster activities have been piloted in the Oulu region since 1995. The results are promising: the industrial product innovations (like multimedia in medicine) of the welfare sector originate from the combinations of social and health care reseach at the Faculties of Medicine, Technology, Economics and Natural Sciences in Oulu, participation of the National Reserach and Development Centre for Welfare and Health STAKES, the needs of the citizens (surveys) and technical advances in fields such as electronics and informatics.

More information of the Welfare Cluster can be found at website
http://www.vtt.fi/tte/welfare_cluster/newhome.html

The client-centered seamless service chain

Concept definition

Finland has adopted the European Standardisation Committee's (CEN) Technical Group TC 37 standards as the working method, when defining concepts such as 'seamlessness'. This tradition of concept definition is widely adopted in Scandinavian countries. This work is done in cooperation with welfare and healthcare authorities and coordinated by STAKES. Some 200 basic concepts have been defined, which is not too many, but the work done is agreed to be fundamental for founding the common conceptual basis for information systems development. To give an example of the work done, let us look at the concept of service chain and seamless service chain a little closer.

There has been a lot of discussion whether these concepts can be used in Finland. They originate from the European healthcare system, where a private practioner is providing services to the population. Our service structure is more complicated with both basic welfare services and healthcare provided by the municipalities, ideally from the same organisation. The chains require the unifying perspective to all services given to a client. We have therefore made a distinction between the model of the seamless chain and the action itself, and also between a model based on a linear time idea connected to chains and a network model, the latter of which is the actual functional model in all chains.

Another important aspect to be mentioned here is the relation between concepts of service and care, and client and patient. All these concepts have also been defined, and we have come to the conclusion that a *patient* is a kind of *client*, that is, a client with medical problems. A client has traditionally more attributes, at least in the Finnish service structure. The same concerns *service* and *care*, care being a kind of service, but the service system also includes various other activities other than care. This means that when defining concepts, knowledge of the local service structure and culture becomes extremely important.

The service chain has been defined as "the entity by the chain of service processes associated with the certain problem or need of the client, crossing the organisational boundaries ". This organisational crossing is actually the only feature which separates chains from processes, in a terminological meaning. Both have at least three phases: proceeding, realization (or implementation) and completion. Besides that, they can have several other phases, like planning, decision making, evaluation, and so on. From the viewpoint of information systems it is of utmost importance that we can concretize both the beginning and the completion – not ending – of the process. From the viewpoint of the client these phases might be of less importance than those of planning, agreeing or making decisions. All the phases consist of one or several service events, which are the smallest documented events in the service process.

The seamless service chain has been defined as follows:

> *Service chain, where client and/or information on him/her is being transferred in a flexible manner from one service process to another and from one organisation to another.*

An additional remark says, that "In these chains all the professionals participating in welfare and healthcare service processes should be aware of the different phases of transferring a client and his/her information, as well as of the needs concerning cooperation and information exchange. Moreover, all the information concerning the client has to be transferred systematically and according to the data security regulations".

Here ends the traditional terminological work. The Finnish addition to this is: information systems, data security and statistical viewpoints, whenever they have been possible. In this special case only the first two have been identified. From the point of information systems the seamless service chain is being defined as:

> *Such an agreed method implemented in information systems which supports planning, steering and evaluating of the chain and with which information connected to the client's service chain is transferred in a planned manner from one service process to another and from one organisation to another according to the data security regulations.*

From the viewpoint of data security regulations the chain is being defined as follows:

> *In seamless chains the principles guiding the managent of information are included in information systems in a way that meets the regulative basis. Information transfer is being carried out primarily based on the client's permission.*

What are the use of these definitions? We have found it very useful to go through this process of setting general frameworks to different phenomena. After this work the meaning of the words becomes more questionnable: what is meant by professional? How to define the essential information needed to carry the knowledge of clients' needs and problems? How to meet the requirements of privacy protection and data security in a certain client process? In other words, the concept work usually opens a mass of new questions, which are very relevant to the client process. The truth is that all we know that a service process and a client case is being documented in information systems. It also has to be there, for the sake of client's and professional's rights. This work has a very pragmatic view: one has to be able to document all the relevant information to be able to use the information again and to repeat the process in case it is needed, e.g. for juridical purposes.

The chain model

The seamless service chain is not just a concept, it is also an operative model in which the service and care required by a client is combined into a client-centred seamless entity surpassing the organisational and administrative limits. The crucial factor in a seamless service chain is distribution of information between the different services - promotion of welfare and health, welfare services, primary care, secondary care, rehabilitation, social insurance - in a way which renders possible the best available implementation of the total care and services needed by the client in the situation. The result will be an effective and appropriate use of resources, a rise in service quality, and the client's increasing participation in decisions and actions. The utilisation of data technology enables a population responsible team or person to act as the client's agent during the service chain.

From the client's perspective the functionality of service chain is manifested primarily by the waiting time for the services. Consequently the processing times for referrals, applications, notifications and the systems for managing internal resources are the central issues. The reason that these factors do not operate in an optimal fashion is due partly to the fact that the content for population responsibility as well as the responsibility for clients who are waiting for the implementation of a service has not been defined in an exact way.

From the organisation's viewpoint, the effectiveness and quality of the services is shown by flexible services during the implementation phase of the unit's internal service process. At this point attention is not paid to how long the client has been waiting for the implementation of the service.

Key issues from the viewpoint of the producer of the service is the availability and quality of relevant data for the implementation of the service. This pertains to data flow both between units and within a unit. Feedback to a public local service unit is arbitrary - only in specialised care is it a general practice for the referring service unit to receive feedback on the patient's care. Of course the referring unit is not always a public local service unit; around 25 % of health care clients in Finland use private primary level services. The performance of the service chain will be optimised from the client's perspective. The operational prerequisites for this have been established by the initiation of regional population responsibility in welfare services and healthcare. Data systems support the implementation of the regional population responsibility principle as well as the successful performance of the service chain entity. In addition, data systems support the client's right to obtain information about decisions that concern him/her.

From the strategic viewpoint the following outputs can be reached by seamless chains:

- The utilisation of data technology enables a regional population responsible person/team to act as the client's agent during the service chain. In effect this means that the person/team is up-to-date concerning the progress of the service chain and can actively have an effect on it if necessary. This will in turn have an effect on the client's waiting times for services. In addition, communication between the client and the responsible persons becomes more effective, thus enabling the realisation of the 'one window' principle. The one window principle means that the client, when they so wish, can always obtain information concerning the progress of their service chain from the same unit, regardless of where a given service was provided or will be provided in the future.
- The development of information services will have an impact on guiding the client to the correct service/care facility, for example in duty and first-aid situations. This will decrease unnecessary visits which also has an impact on service costs in the long run.
- Appointmentsn will be scheduled in the best possible way if the client can book them themselves. This affects the client's use of time, which for its own part decreases appointment cancellations and thus impacts operational efficiency and costs.
- The above activity necessitates increased education for special groups (elderly people and the physically and mentally disabled and other populations using welfare and healthcare services. Clients' activity in the utilisation of data technology may lead to increased inequality between clients. This may be avoided by developing alternative models for those people who do not have the possibility of acquiring or using data technology equipment.
- The facilitation of data acquisition in a regional population responsible unit concerning, e.g. service availability, prices and quality will affect the costs of client-specific service chains.

Case management in chains

The purpose of client-centred seamless service chain is to reform the traditional organisation-centred operational procedures in welfare and healthcare and to improve the availability and efficacy of these activities. The question is, who is to coordinate the services in this new model? Who will, on behalf of the service producer, synchronise the processes, taking effectiveness into consideration, and at the same time act in a client oriented manner on the surface of the service iceberg, which should be invisible to the client as a series of processes but at the same time flexible and individual?

Case management has been mentioned in the new Goverment Program, established in April 1999. The program says that case management has to be strengthened especially in welfare and healthcare services used in the care of chronically ill and disabled people. A lively discussion on this topic immediately started in the press, and several professional groups announced their interest in acting as such a case manager.

It has been estimated that, within the Finnish education structure, this task would best be suited to social workers or rehabilitation professionals. When also a large selection of social insurance allowances are included in the chain of both elderly,

chronically ill and disabled, there should be a person more like a 'process director' than that of a highly competent professional either in allowances or welfare and health services.
The Macro Pilot project is now preparing to pilot both the so called 'Service Manager' and also the 'Case Manager' for disabled children. The requirements from the different viewpoints are now under definition: such as thecompetence of a person; data security consequences of the work; organisational status of the professional; as well as the work division between different managers and their duties.

Conclusion

A wide range of activities in the field of developing information technology in Finland is now in process. Finland has good opportunities to succeed since all the central actors work in cooperation. Because the state management is informative by nature, except for the support given to the development activities through the state budget, the main stress on activities lies on municipalities and joint municipalities. They have also taken the challenge and started several projects developing information technology applications. The common aim in these projects is to be more client orientated in the service processes, because it is seen to be the only possibility to keep the existing service level within existing financial resources.

More information of the Satakunta Macro Pilot and other projects can be found at website http://www.oskenet.fi/eike/e/projects/index.html

Developing a computer supported evaluation system in a human service organization

by Peter Gabor and Jackie Sieppert

Abstract

Facing growing demands to improve their effectiveness and to become more accountable, human service organizations are paying increasing attention to evaluation. The most effective evaluation approaches are internally driven, rely on continuous data collection, and emphasize development rather than judgement. With modern computer technology, even small organizations have access to customized information systems, which can provide them with such an evaluative function. This paper describes the process of designing and implementing an information system, maintained on a Microsoft *Access 97* platform, at a relatively small family serving organization. In addition to a detailed description of the system and the corresponding database structure, the paper also describes and examines the human and organizational considerations involved in introducing the system.

Introduction

In the decade of the 90's social and human service organizations have been under considerable pressure to improve the effectiveness and efficiency of programs and to respond to demands for accountability. Organizations have thus paid increasing attention to evaluation, which is the primary means of generating the information needed to support the quality improvement process and to meet accountability demands.

The greater availability of computer hardware has put customized evaluative information systems within the reach of even smaller social service organizations. Although developing such systems may require a considerable investment in time, effort and resources, once established, such systems can operate without a great deal of maintenance and produce a stream of strategically selected information at relatively low cost.

The Family Centre in Lethbridge, Alberta, Canada is a non-profit organization providing a variety of services, including parent support, education, parent-teen mediation and counselling. Three years ago, the organization embarked on developing an evaluation system that could produce the information needed for continuing quality improvement and for accountability

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purposes. The authors, as consultants, assisted the organization in the design, development and implementation of this system.

This paper will outline general considerations in designing and developing evaluation systems for human service organizations. Next, the design and implementation process of the Family Centre system will be traced and the system will be described. Finally, the experience will be examined with a view of identifying issues and considerations in designing information systems for human service organizations.

Information technology and evaluation

Information technology in the human services

Information technology was introduced to the human services about 35 years ago (Hudson, 1993), with a focus on management information systems, used to facilitate planning, program development and evaluation functions. Cwikel & Cnaan (1991) call this the "first wave" of information technology in the human services. It dominated discussion and research for almost three decades, until a "second wave" of technology evolved, consisting of expert systems, computerized simulations and games, and software meant to facilitate interviewing, assessment and client monitoring (Miller, 1986, Nurius & Nicoll, 1989).

Even with the arrival of the second wave, first wave applications continue to be important. Driving the use of management information systems are not service delivery considerations, but demands for accountability from funders (Bolitho & Smith, 1988). These demands seem to give a single directive to human service providers — incorporate technologies that hold the greatest promise for enhancing effectiveness and efficiency. In particular the computer's ability and capacity for processing data has been seen as a vehicle to improve decision-making and evaluative processes.

Grasso & Epstein (1993) point to a number of presumed benefits of information systems. Computerization and the use of resulting data are said to provide senior managers and policy-makers with the information required to define policy, set goals, engage in planning, and achieve accountability. Mid-level managers and supervisors benefit by being able to use computer generated data for allocating, monitoring, and controlling agency resources. Front line personnel find relief from having to perform routine tasks that are now handled more easily and faster by computer systems.

Ackerman (1995) argues that computer systems will form an essential part of social work delivery, and that human service organizations need to view computers as a means of optimizing services. However, Pardeck et al. (1995) have found that computer technology has not generally been warmly embraced. These results are not unique, as studies by Mandell (1989), Mutschler & Hoefer (1990) and Savaya & Waysman (1996) have also concluded that human service professionals and organizations do not make extensive or effective use of computer technology.

Clearly, more work needs to be accomplished in developing context and field specific applications and in increasing technology adoption. Information systems that can organize and manage evaluation activities continue to be a promising direction for such work, because information systems help organizations to make an effective response to the challenges posed by the demands for effectiveness and accountability.

Evaluation in the human services

Traditionally, evaluations have been organized as projects, initiated outside of the organization, undertaken periodically, and implemented by external experts. (Gabor, Unrau & Grinnell, 1998; Posavac & Carey, 1997) This approach often resulted in a technically oriented report, focusing on a few selected objectives, issued long after the project was completed. Such reports were often ignored both inside and outside of the organization. (Chronbach, 1980) Because each evaluation was a unique project, a variety of data collection instruments and protocols was designed specifically for each effort. This created considerable disruption within the organization and imposed a significant burden on staff members who were usually charged with data collection responsibilities. In short, traditional evaluation approaches demanded high investment and returned sporadic feedback that was often too late or too non-specific to effect decision making.

To ensure the availability of appropriate feedback, a different approach to evaluation is required. This approach, known as monitoring, emphasizes continuous data collection and is based on the idea that evaluation is feedback. (Gabor & Grinnell, 1994) Essentially evaluation becomes a continuing activity, with a focus on effectiveness and development (Attkisson & Broskowsky, 1978) rather than judgement. It is most appropriately carried out internally by staff members as an activity that is integrated with their ongoing responsibilities, rather than as an additional responsibility separate from normal duties. (Gabor, Unrau & Grinnell, 1994) Monitoring systems tend to be more attuned to organizational context, less disruptive to normal operations and, because of the continuing availability of information, more effective as feedback systems.

In developing an effective monitoring system consideration must be given to the selection of the data that is to be tracked. At the program level, evaluations may focus on needs, process, outcome or efficiency (Royse & Thyer, 1996; Posavac & Carey, 1997.) For purposes of quality improvement and accountability, the most important of these focal points are process and outcomes. Elements of process evaluation may include information about client characteristics, activities and service statistics, quality standards, and feedback from program participants. Outcome evaluation focuses on the results of the program which are always outside of the organization. (Drucker, 1993) That is, results describe changes to individuals, families, groups, and communities.

Designing and developing an effective information system is not only a technical matter; human and social issues also need consideration. Staff members, as human beings, may have reactions that range from skepticism to resistance when faced with the introduction of an information system. These reactions are related not only to the personality and experience of the individual but also to the collective experience of the work group and the organization. Where recent experience includes: reorganization, restructuring and questionable use of previous evaluation results, staff members will understandably react with suspicion if not outright hostility. Negative reactions may be exacerbated when staff members do not have an adequate level of computer literacy, as is often the case (Pardeck et al., 1995.)

It is a key leadership task to create an organizational environment within which evaluation can be a constructive activity. A foundation of such culture is the principle that the resulting information will be used for purposes of development rather than of judgement. In such a culture risk is allowed and failure leads to learning and future improvement (Senge, 1990); evaluation information is welcomed as feedback, valuable for making future decisions. Organizations with constructive evaluation cultures pay particular attention to helping and supporting staff members in their efforts to contribute to and function effectively within such a learning environment. (Gabor, Unrau & Grinnell, 1998)

The Family Centre system

Developing the system

The project described in this paper was initiated by the Executive Director, who recognized the need for a comprehensive information system within her organization. After initial discussions with the consultants, the main characteristics of the system were specified:

- The system should be internally designed and operated;
- Evaluation activities should be ongoing with continuous data collection and reporting;
- The system should make use of data collected during service provision;
- There should be a focus on both process and outcomes;
- The system should be development oriented and provide feedback for decision-making;
- The system should provide information that can help the organization respond to accountability requirements;
- The system should be automated to the extent possible; and,
- The design and implementation process should not be disruptive.

Discussions between the Executive Director and the consultants revealed the existence of a relatively rudimentary system, managed by an outdated spreadsheet program, that could provide limited summary and descriptive information. Data collection was specific to the needs of this system and was not integrated with service provision. It also became clear that most staff members were uncomfortable with the idea of a comprehensive evaluation system, expressing concerns that the requirements of the system would dominate their work and require them to change the way they related to program participants. Although for the most part they were not technophobes, many staff members were wary of the introduction of computer technology, apparently believing that it was inconsistent with the deeply humanistic philosophy of the organization.

These early discussions underlined the importance of human considerations in designing this system; indeed, it became clear that, initially, human considerations would be more important than technical ones. As the agency was interested in preserving its work processes and collegial work environment it was decided that the new system should combine paper and computerized processes. At the field level, where staff interact with the system, the new system would be based on paper forms, while at the central, organizational level, where data is managed, analyzed and reported, the system would be computer based. Thus service providing staff members could continue to work as they always had, completing paper forms appropriate to each phase of service provision. Although the only visible change staff members would experience would be a set of new forms, at the central level, the paper data would be converted to an electronic format and entered into a computerized database, making far more sophisticated and powerful analyses possible.

The planning and implementation phases of the project were designed with three objectives in mind: 1) developing staff commitment to the project; 2) conceptually designing the system to reflect and preserve agency work processes and relationships; and, 3) identifying key indicators of activities and outcomes and designing for the generation and capture of these data.

Winning staff commitment

An internally operated system cannot be sustained without considerable staff commitment. In the case of the Family Centre, the challenge was to turn initial skepticism, reluctance and resistance into commitment. The strategy for accomplishing this was to involve staff members in all phases of the design and implementation of the information system. The planning process showed a genuine respect for the views and perspectives of staff members and the design of the system reflected the information they brought to the planning process. Through their involvement in planning, staff members increased their understanding of information systems generally and how the information system would work in their setting. Maintaining paper forms at the field level also meant that staff members would not have to deal with major changes in their work routine. Staff members were also able to see that great care was taken to ensure that the information system would reflect service priorities. Thus, their fear that the information system would somehow transform the way they worked abated and, in fact, staff members began to see the potential value of the system not only to the agency but also in their own areas of responsibility.

Developing a conceptual framework

A second element in designing and implementing the system involved the analysis of goals, objectives and activities for each program. There existed considerable documentation about the mission and goals of the organization but the objectives and activities of each program were less clearly specified. As evaluation takes place at the level of objectives and activities, clarifying and reaching agreement on objectives and activities is critical. A series of lengthy staff meetings was held, supplemented by the work of small task groups and agency managers, in making explicit program goals and the objectives and activities that relate to these. The result was a document that provided a comprehensive listing of what each program was attempting to achieve and the means by which it went about doing so. Most staff members felt that the exercise of clarifying goals, objectives, and activities greatly improved their understanding of their program.

This exercise also put the group in a position to determine which objectives and activities should be monitored and tracked. As the initial listing contained dozens of objectives and hundreds of activities, it was clearly unfeasible to track all of these. The challenge was to select the objectives and activities of greatest importance; these would serve as indicators of the performance of each program. After considerable deliberation, the objectives and activities to be monitored were identified.

Designing data collection instruments

After listing the objectives and activities around which the information system would be built, the analysis turned to the existing data collection instruments within the organization. A number of forms were in use to collect data at various points in service: intake, contact, and service termination. These forms gathered some of the data that was selected for the information system. However, overall, the data collection forms had developed over a period of years in a relatively unplanned manner, resulting in considerable duplication, inconsistent formatting and the omission of data relating to the targeted objectives and activities.

It was agreed, therefore, that the forms should be completely redesigned, to ensure that all objectives and activities of interest could be tracked, to reduce duplication, and to increase consistency in paperwork among programs. The consultant led staff teams through the process of redesigning the forms. Early drafts were brought back for comment and critique and were modified according to the feedback received. Many changes to content, wording, sequencing and layout resulted from this process. Finally, after several rounds of feedback, pilot forms were completed and tested in the field. After one more round of feedback and modifications, the paper forms underlying the system were implemented within the agency.

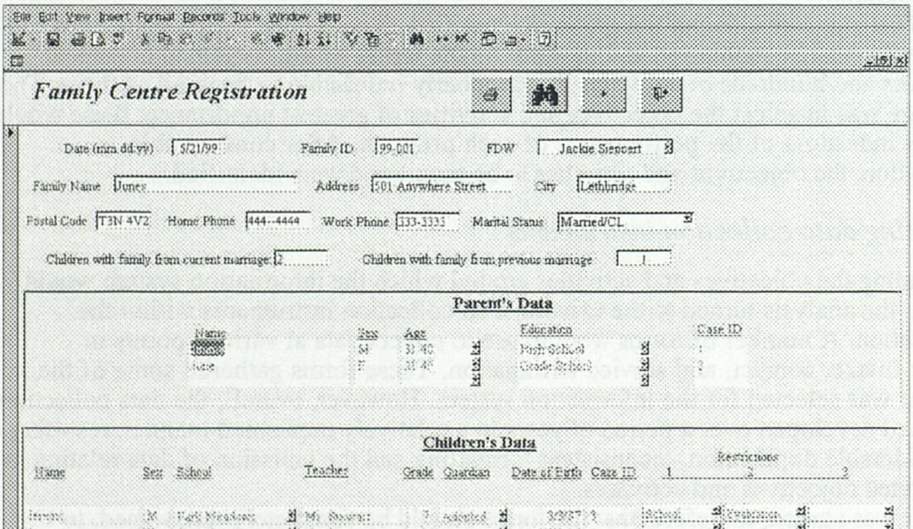
Description of the Database

The heart of the Family Centre information system is a fully relational database, based on a Microsoft *Access 97* platform. This platform is flexible to program and has a relatively friendly user interface. Using data in key fields as linkages between disparate information about the families and individuals receiving services, the system makes relatively sophisticated queries possible. Currently, the data collection is accomplished using paper forms; the data are subsequently entered into the database, which maintains an electronic versions of all paper forms.

The database is structured into seven distinct areas: 1) a central registration area to record core family data; 2) intake information recording specific case intakes and initial service decisions; 3) contact details for all open cases; 4) contacts made through service groups; 5) actions, rationales and follow-up details for all cases being closed; 6) satisfaction and feedback forms completed by clients; and 7) automatic reports generated for the first six areas.

The core of the system is the registration area, as shown in Figure 1. All families are assigned a Family ID, which serves as the primary key or identifier for the entire database. This makes all transactions within the database traceable back to a particular family, even if only one member of the family receives services. The Family ID key also allows the Family Centre to look at patterns of service delivery for both individuals and family units over time.

Upon registration, a family development worker (FDW) from the agency is assigned. This worker records all relevant demographic information about the family, as well as specific information about each family member. Family member information is collected for both the parents and children, and these data are stored in two separate sub-tables for these groups. This allows for observation of patterns in the data for



Family Centre Registration

Date (mm/dd/yy) 5/21/99
Family ID 99-001
FDW Jackie Siepert
Family Name Jones
Address 501 Anywhere Street
City Lethbridge
Postal Code T3N 4V2
Home Phone 444--4444
Work Phone 333-3333
Marital Status Married/CL
Children with family from current marriage: 2
Children with family from previous marriage 1

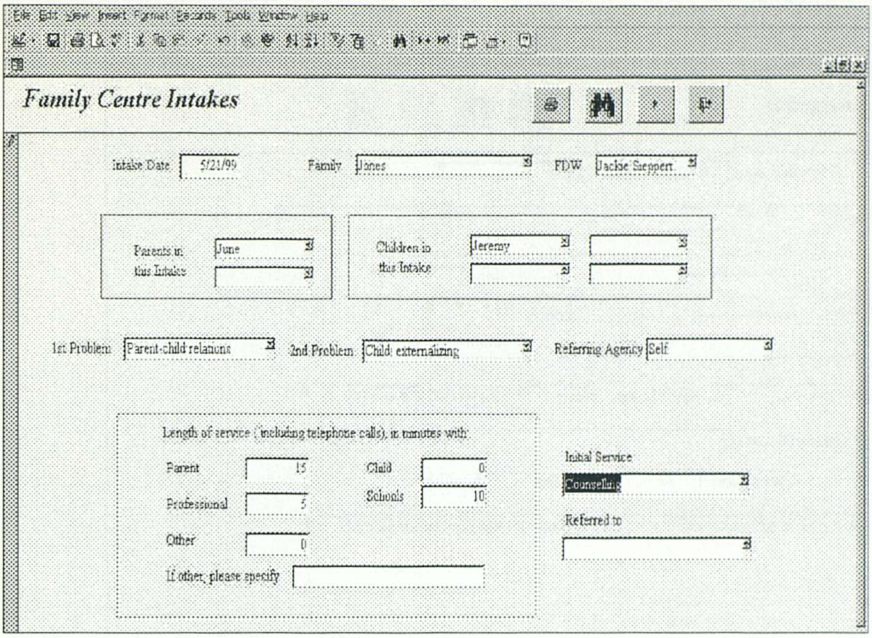
Parent's Data

Name	Sex	Age	Education	Case ID
[illegible]	M	31-40	High School	1
[illegible]	F	31-40	Grade School	2

Children's Data

Name	Sex	School	Teacher	Grade	Guardian	Date of Birth	Case ID	Restrictions 1	Restrictions 2	Restrictions 3
[illegible]	M	Park Meadows	Mr. Stewart	[illegible]	Adopted	3/3/87	3	School	Probation	
[illegible]	F	Park Meadows	Mr. Green	[illegible]	Biological	12/12/89	4			
Katherine	F			[illegible]		5/13/94	5			
				0						

Figure 1 - Family Centre Registration Form



Family Centre Intakes

Intake Date: 5/21/99
Family: Jones
FDW: Jackie Sieppert
Parents in this Intake: June
Children in this Intake: Jeremy
1st Problem: Parent-child relations
2nd Problem: Child: externalizing
Referring Agency: Self
Length of service (including telephone calls), in minutes with:
Parent: 15
Child: 0
Professional: 5
Schools: 10
Other: 0
If other, please specify:
Initial Service: Counselling
Referred to:

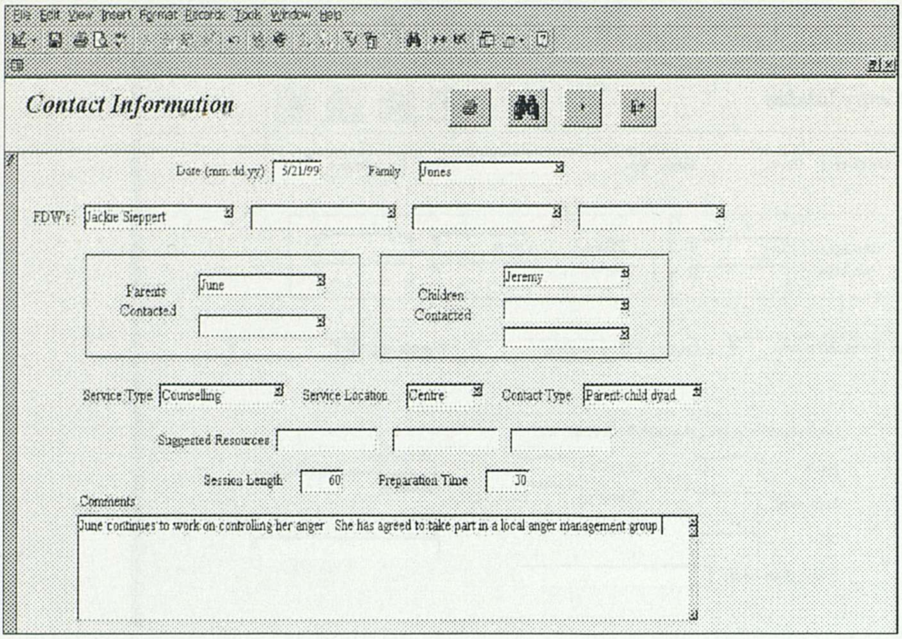
Figure 2 - Family Centre Intake Forms

parents and children separately. Data for each parent include name, sex, age, and education level. Data for each child include name, school information, age, type of guardianship (biological, adoption, foster child, etc.), and any restrictions that might be placed on information sharing or service delivery. In addition to the central Family ID, each family member is also assigned a unique Case ID. This Case ID is a secondary key which is used throughout the database to track service transactions on an individual level.

Not all families who initially register for services actually enter the service stream at the Family Centre. Some families will resolve issues through other means, others will seek service from other providers, and some family issues are deemed to be inappropriate for the types of services the Family Centre has to offer. For this reason the actual start of a service transaction is recorded in the intake portion of the database, as shown in Figure 2.

Upon initiation of an intake, a service worker is assigned. This worker records the date of the intake and the specific family members to be involved in the service transaction. As in other areas of the database, the intake form makes extensive use of lookup tables. By clicking on the Family ID lookup table the service worker is shown an alphabetical list of all registered families, along with their Family ID. A click on the appropriate family will result in the family's name being shown on screen, while in the background the Family ID is saved into an 'intakes' table. Once the appropriate family is chosen for an intake, the list of available parents and children is restricted to that specific family, making it easy to record which individuals will be part of the service transaction. Again, individuals' names are displayed on screen, but Case ID's are stored in the 'intakes' table for further use.

In addition to the individuals involved, the intake form also records the two identifying problems considered to be most pressing at the initial assessment point. The worker also records the referral source (including self-referral), the type of service to be initiated (such as counselling, information provision, support group or family mediation), and the length of time spent with various constituents in processing the initial intake.



Contact Information

Date (mm/dd/yy) 5/21/99
Family Jones
FDW's Jackie Sieppert
Parents Contacted June
Children Contacted Jeremy
Service Type Counselling
Service Location Centre
Contact Type Parent-child dyad
Suggested Resources
Session Length 60
Preparation Time 30
Comments
June continues to work on controling her anger She has agreed to take part in a local anger management group

Figure 3 - Family Centre Contacts Form

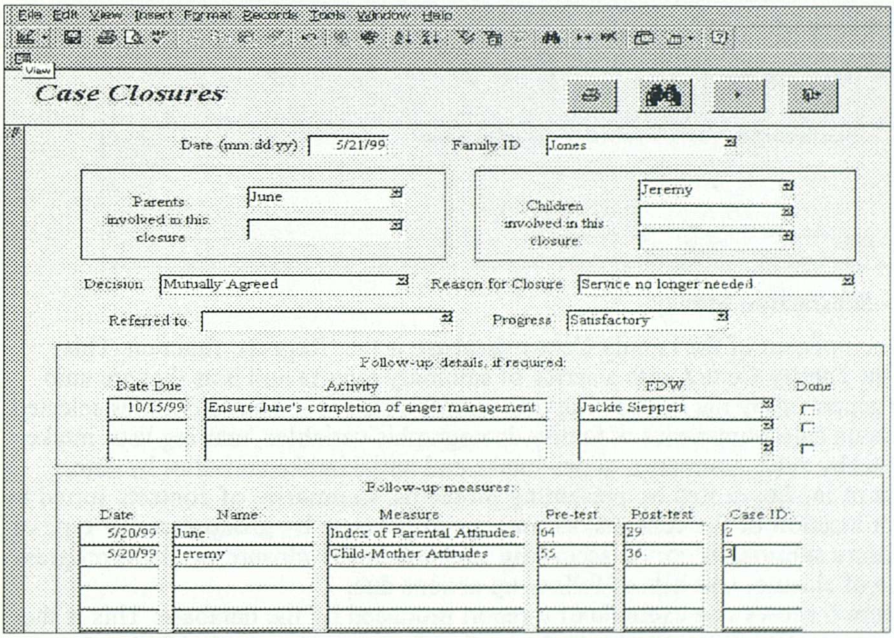
Once families and individuals complete the intake process, the next two components of the database are focused on the services provided. The contacts form, shown in Figure 3, is used to record the date and service worker(s) for each contact. Family ID and individual Case ID numbers for each individual involved in this particular contact are also recorded. Once again, full names are displayed on screen and ID numbers are stored in the background. Details of the service provided during the contact are also recorded. These include the type of service (counselling, mediation, etc.), the service location (Family Centre, phone, school, or other), and the contact type (collateral, couple, family, individual parent, individual child, or parent-child dyad contacts). Finally, any outside resources that are recommended during the contact are also recorded, as is the time it took to prepare for and conduct the particular contact.

The other type of contact information stored in the database is that for group contacts. This information is similar to the contacts described above, but with all participants of a group being recorded instead of specific family members. In addition, the specific name of the group is recorded, along with the type of group (such as education groups for parents or children, or support groups). These details allow the Family Centre not only to collect descriptive data about group services, but also to attribute group level services to individuals (and families).

The final transaction-based component of the database is the closures form (Figure 4). This form relates back to the intake process and information. That is, it records closure of cases that were recorded in the 'intakes' form, leaving both basic family and individual information in the registration area of the database should further service delivery be required at a later point. As in the other transaction-based forms, the closure form is anchored by recording the Family ID and Case ID's of the intake being closed. In the background a check is made to match these with a hidden intake number to ensure consistency in the database. Details about whether the closure is the client's decision or a mutual worker-client decision is recorded, as is the reason for the closure (service is no longer required, the client stopped coming, further service is declined, the client is referred elsewhere, etc.). A worker rating of the client's progress is also made, using a scale that ranges from unsatisfactory to excellent.

At this time any required follow-up activities are also recorded for the case. This includes a date upon which follow-up is due, the specific activities to be performed, the worker who is to perform them, and a simple check box to record that the follow-up actually took place. Once an intake is marked for closure a number of actions may be taken. These include marking closed intakes to bring forward for follow-up action, deleting closed intakes from the database, or archiving closed intakes for storage elsewhere.

The 'closures' form also serves as the core of the outcome evaluation process. A central feature of this evaluation process is the recording of data related to assessment measures used during the time the case was open. The date, name and Case ID involved in each administration of an evaluative assessment measure are recorded on the closures form. In addition, the specific measure used (a variety are available), and both pre and post-test scores for this measure are documented. This process allows the Family Centre to track administration of its assessment instruments, and analyze progress as determined by differences in pre- and post-test scores over time.



Case Closures

Date (mm:dd:yy) 5/21/99
Family ID Jones

Parents involved in this closure: June
Children involved in this closure: Jeremy

Decision: Mutually Agreed
Reason for Closure: Service no longer needed
Referred to:
Progress: Satisfactory

Follow-up details, if required:

Date Due	Activity	FDW	Done
10/15/99	Ensure June's completion of enger management	Jackie Sieppert	☐
			☐
			☐

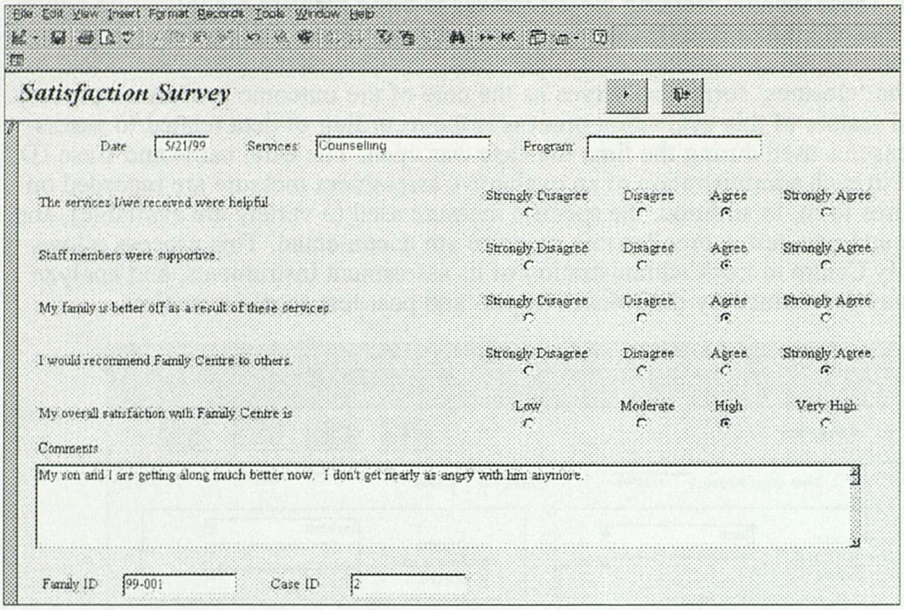
Follow-up measures:

Date	Name	Measure	Pre-test	Post-test	Case ID:
5/20/99	June	Index of Parental Attitudes	64	29	2
5/20/99	Jeremy	Child-Mother Attitudes	55	36	3

Figure 4 - Family Centre Closures Form

Three other forms also contribute to the evaluative components of the database. These allow for information collection and reporting about the perceived effectiveness of the Family Centre's services. These include an 'Education Program Feedback' form, a 'Parent Support Feedback' form, and a 'Satisfaction Survey' form. Each of these allows service recipients to respond to a brief series of questions that ask about the quality and effectiveness of the services they received.

The Satisfaction Survey is one example of this process. This form allows clients to sit at a computer and complete an on-line survey or an equivalent pen and paper survey that will be entered by clerical personnel at a later time. As illustrated in Figure 5 clients are provided with five simple questions about the helpfulness of the services they received and their overall satisfaction with the Family Centre. Along with that, brief descriptors of the services they received and programs they have participated in are recorded. In the background, client responses are converted to numerical ratings, which can then be used to calculate descriptive statistics for individual services, programs, or the agency as an entity.



Satisfaction Survey

Date: 5/21/99
Services: Counselling
Program:

The services I/we received were helpful	Strongly Disagree ○	Disagree ○	Agree ●	Strongly Agree ○
Staff members were supportive.	Strongly Disagree ○	Disagree ○	Agree ●	Strongly Agree ○
My family is better off as a result of these services.	Strongly Disagree ○	Disagree ○	Agree ●	Strongly Agree ○
I would recommend Family Centre to others.	Strongly Disagree ○	Disagree ○	Agree ○	Strongly Agree ●
My overall satisfaction with Family Centre is	Low ○	Moderate ○	High ●	Very High ○

Comments: My son and I are getting along much better now. I don't get nearly as angry with him anymore.

Family ID: 99-001
Case ID: 2

Figure 5 - Satisfaction Survey

The final component of the Family Centre database is the 'Reports' function. This provides the Family Centre with a series of summary reports and lists that are automatically generated by the system. Reports include lists of registered families selected by registration date, summaries of family demographic variables, mailing lists, intake lists selected by date, summaries of pre-intake and initial intake activities by date, summaries of intakes sorted by presenting problems, summaries of contacts sorted by the type or location of the contacts, summaries of contacts by group name or type of group, closure summaries sorted according reasons for the closure or client progress at the time of closure, and lists of follow-up actions due.

Figure 6 shows one example of a report produced by the database. This is the 'Contacts by Contact Type' report. It shows that between January 1, 1998 and January 1, 1999 there were 1915 contacts made with clients. Almost 80% of these were in the form of individual contacts between workers and children (35%) or workers and parents (45%). Collateral contacts formed about 10% of all contacts, and couple or family contacts were relatively rare (each forming approximately 4% of all Family Centre contacts). The report also shows that there were significant differences in the time demands placed on workers for the different types of contact. On the average, individual parent contacts took only 12 minutes to prepare and 34 minutes to conduct, totaling 46 minutes. Individual child contacts, on the other hand, took much longer to prepare (36 minutes) and much longer to conduct (53 minutes), for a total of almost 89 minutes, or roughly double the length of parent contacts.

Contact Type	Number of Contacts	Percent	Average Session Length (in minutes)	Average Prep Time (in minutes)
Collateral	205	10.67%	22.4	13.1
Couple	70	3.64%	73.6	28.6
Family	75	3.90%	56.6	38.1
Individual: child	678	35.28%	52.5	35.5
Individual: parent	836	43.50%	33.5	12.0
Parent-Child dyad	48	2.50%	50.9	28.8

Figure 6 - Contacts by Contact Type Report *From 01-Jan-98 throught 01-Jan-99

Results such as those provided in the 'Contacts by Contact Type' report provide highly practical and useful feedback to staff members and managers. For example, the Family Centre is philosophically committed to build the family unit; staff members have a strongly held belief that the most effective services are those that are provided to the family as a whole or, at least, to some relevant grouping within the family. The results shown in Figure 6 indicate that actual practice is not consistent with the agency philosophy. These results challenge the team to examine their practices carefully, to determine if modifications are required in order to increase the percentage of services provided to the family unit. Taking a hard look at prevailing practices, and modifying them as appropriate, is at the heart of the quality improvement process. The information system will continue to generate reports; these provide feedback on the effectiveness of the measures taken to improve the situation.

In addition to predefined reports, custom analyses can also be generated, by entering specific parameters to form query details. Thus specific variables or relationships between variables can be examined. This facility permits more detailed examination of issues uncovered through the routine reports as well as the investigation of new issues. The focus of evaluative feedback can thus change as circumstances indicate.

Conclusion

Information systems should not be viewed in isolation; they are most meaningful in the context of organizational processes and structures. Successful implementation of an information system requires attention to human, organizational and technical matters.

First it is vital to determine the purpose and function of the information system and how it will fit into organizational processes. Next, it is important to assess staff readiness and needs, and design an appropriate implementation process. Only after these considerations can a technical solution be developed; a key part of the technical solution is to determine to what extent and at what pace to incorporate information technologies.

Human and social systems function best when ongoing well targeted feedback is available. Such feedback provides information about the effectiveness of past efforts, thereby providing the opportunity to adjust future activities in order to maximize effectiveness and efficiency. Social service organizations are human and social systems; timely, continuous, pertinent feedback will promote the effectiveness of the organization and help programs and services meet their objectives.

Effective information systems need to be acceptable to staff members, who are inevitably involved both in the collection of data as well as in its utilization. It is important that the introduction of the system be non-threatening and that staff members be allowed the time to become accustomed to the introduction of a powerful information system. The Family Centre system was designed as a comprehensive monitoring system, internally operated and involving continuous data collection. It was introduced through a process that took care to involve staff members in planning and was sensitive to their desire to preserve the way they interacted and worked with clients. Although the system can accommodate direct data entry by staff members, the use of paper forms was maintained for the time being, due to a perception that direct data entry would demand too many adjustments to work processes and relationships. It is planned, however, that in time, with further development of staff attitudes and skills and the greater availability of hardware, direct data entry will be adopted and the use of paper forms will be minimized.

Although only partially relying on computer technology, the Family Centre information system is powerful and sophisticated. It meets all the criteria identified in initial planning and is able to track data relating to client characteristics, activities and service statistics, quality standards, feedback from program participants and outcomes. Not only does the system have this capability but, because of the attention paid to human and organizational issues, it has become integrated into the culture and processes of the agency. The information produced serves to improve the quality of decisions, provides a better understanding of programs, creates a sense of control and empowerment within the organization, and helps to meet accountability requirements.

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Closing the gap between central and local authorities for welfare and health

by Anni Hakkarainen

Abstract

The Municipal Database for Social and Health Statistics in Finland (SOTKA) covers the statistics produced for local use by social and health services. About 60 % of the municipalities use this database. It was found that the best way to promote the diffusion of information is a network connecting the providers and the users of statistics. The experiences are encouraging.

Introduction

'Sotka' is the name of a mythical bird who according to the Finnish national epic, the Kalevala, created the cosmos, but it also is the first name of the *Municipal Database for Social and Health Statistics in Finland* (SOTKA). This database covers most of the statistics produced for local use by social and health services. SOTKA has created a data 'cosmos', a data matrix of 3300 items of information times 9 years times 450 municipalities. Every year this cosmos grows. The database has its 'nest' at STAKES, the National Research and Development Centre for Welfare and Health.

In Finland, the normative and financial power of national authorities has diminished during the last decade while the decision-making power of local authorities has increased. By law the municipalities are responsible for the provision of social and health services. They either produce services themselves or buy them from other producers. How the local responsibility is met is determined by the local authorities, the market forces, and the citizens' own voluntary organizations. These actors need information support in their transactions (Hakkarainen A. 1996). SOTKA data are open to everybody. The purpose is to support local democracy.

SOTKA's users

SOTKA was started in 1995; currently there are almost 700 SOTKA users. The user categories are given in Table 1 (overleaf).

In Finland there are 5,150,000 people who live in 450 municipalities. SOTKA is used in 270 of the municipalities, an acceptance rate of about 60%. What might be the reasons for the slow diffusion of this statistical innovation?

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User Category	Number of Licences
1. Municipalities, NGOs and private sector	**378**
Municipalities	306
Joint boards of municipalities	54
Non-governmental organisations	16
Private firms	2
2. Education	**29**
Universties	13
Institutions for social & health education	16
3. State administration	**247**
Ministry of social affairs and health	75
STAKES	109
Provinces	27
Others	36
4. Others	**26**
Total	**680**

Table 1: Number of Sotka licenses by user category in March 1999

The gap between the database and the user

Statistics in demand?

SOTKA was meant to be an instrument for small municipalities. About 90% of all municipalities have less than 20,000 inhabitants, and 75 % have less than 10,000. The municipality populations vary from 130 in Sottunga to 540,000 in Helsinki. The average size of a rural commune is about 5000 inhabitants. Some municipalities are really so small that they do not need many statistics. Although the social and health services may cover 50% to 60% of the municipal budget in the smallest municipalities the local authorities do not always see the importance of having immediate access to such a statistical database. They can get their statistics ready-made from the regional organizations.

At the other end of the scale there are the big cities which have their own statistical offices. They often do not want to compare themselves with small municipalities but rather with other cities of equivalent size or with cities abroad. For this kind of comparison they need much more detailed statistics than those that SOTKA can offer. In order to avoid empty cells in the statistical tables for small municipalities, SOTKA classifications are rather broad. In this way information protection for individuals is assured. In the statistics for a small municipality an individual cannot hide in the mass of numbers as they would in the data for a larger municipality. Anyway, all the big cities have at least one SOTKA license. SOTKA is their easiest, least expensive channel to national statistics regarding social and health matters.

What about the price?

Is money the problem? The price of a SOTKA license is 4200 FIM, about 705 EURO, but during a campaign in 1997-1998 the Ministry of Social Affairs and Health offered SOTKA to the municipalities free of charge. After having lost most of their normative and financial power over the local authorities, the national and regional authorities hope to guide the health and social service development by providing information. The free delivery of the licenses increased the number of municipal users from 21 to 305.

Money matters.

The running costs of the SOTKA service are not high. The monthly fee is 100 FIM, which comes to 1200 FIM or about 202 EURO per year. It covers only the costs of computing the statistics which themselves are given free of charge. This fee covers 12,000 variables per year per user. Over this limit the price reduction is 50%. This price support is authorised in the state budget. Normally statistics are sold at the market price. High running costs cannot be the cause of the indifference towards SOTKA; Only one municipality has renounced its license for that reason.

Technical problems?

Technical problems might also come into question. SOTKA technology is based on the principle of Generic Statistical Message (GESMES). The service uses the international EDIFACT standard (Electronic Data Interchange For Administration, Commerce and Transport) and the *ORACLE* program. It was the most modern system known four years ago. Internet technology is not used in the data dissemination. The user makes an order to the database with their own PC and the database sends the data after a while. The length of the waiting time depends on, e.g. the amount of data ordered and length of the queue. Usually the waiting time is quite short, 10 to 30 minutes.

A bigger problem is that the user interface must be updated every time there are changes in the information content of the database, usually once a year. The new diskettes must be mailed and installed onto the user's PC which is not very convenient.

The user must have a connection with the database using TCP/IP-protocol. There must be a stationary address for the user so that the database can send the message to the right PC and send the bill to the right client. This means that the potential users have to agree a contract with some firm in the telecommunication business. Service via the Internet would be easier but it is not possible at this time. Therefore a third technical factor comes between SOTKA and the user. This was a problem especially at the beginning of the SOTKA era when telematic data transmission was a novelty in local administrations. Hopefully, these problems will disappear after the turn of the millennium when SOTKA moves on to the Internet. It will be a major technical innovation.

What about the content?

Is it the information content of the database that matters? Is the user satisfied with the variety, quality, and the timeliness of the statistics? SOTKA covers a wide variety of statistics in the field of social and health services. The following topics are covered:

- general background
- population statistics
- families and housing
- morbidity and mortality
- social risks and challenges
- social and health budget
- work force in social and health services
- the clients, the patients, and the services provided

The unit of observation is the municipality. The number of variables per municipality and per year is now 3,300, and the years from 1990 on are covered. About two thirds of the variables are raw data which need further editing by the user. The rest are ready-calculated indicators, e.g. percentages and standardized indices.

At the start of the SOTKA project in 1994, administrators from the municipal and national level were appointed to the advisory group for the developers of SOTKA. A questionnaire was sent to the users in 1996 regarding the user interface, the content of the database, and its quality. The results were predominantly positive. This survey will be repeated this year and a project started for the improvement of SOTKA's quality.

For the user the uppermost problem seems to be the timeliness of the statistics. Here we are at the mercy of the producers of the data. The statistics come from about 20 different statistical sources all the year round and are updated when they arrive. STAKES is in charge of its own statistics and the running of the service and would run more efficiently with more staff. There are 3 part-time members on the SOTKA team.

According to the experience of the SOTKA team at STAKES, the real gap lies in the cultural distance between the central and local administration. Local administrative culture has not been accustomed to masses of statistics and high-tech solutions. Interaction between the keepers of the database and the users is a must.

The gap is closing

Statistical publications

Telematics is but one way to keep contact over the barriers of space, time, and social status. The central authorities can approach the local people with the aid of publications, by having common projects, and by arranging seminars, exhibitions, and training courses.

The SOTKA team has been active in all these fields. STAKES itself is the most active user of the database. There are some statistical products that are directly built on the SOTKA production-line. The national program for the targets and tasks in the field of social affairs and health for the next four years uses SOTKA statistics (Valtioneuvosto 1998). STAKES' report on social and health services includes a large statistical appendix (Hakkarainen A. 1997).

For the individual municipality STAKES offers STAKES Municipal Statistics 199x (Hakkarainen A. 1998a and 1998b). It is a yearly publication which has been tailor-made since 1996 for each municipality. The municipality itself can choose the region or the other municipality with which it will compare itself. The main issue in the report is a benchmarking system where the municipality in question is compared to the whole country and to the selected region. In 1998 the number of publications sold was 218.

For the provinces STAKES produces detailed municipal statistics on some vulnerable client groups, e.g. mental patients, the elderly, cases of child protection, and drug and alcohol addicts. Five provinces (regional state government) and STAKES are partners with the municipalities in a national network for the development of services for vulnerable groups. The province administrators do the evaluation on the basis of statistics and their own professional expertise and experience. They have close contact with the municipal officers, the clients, and the local people.

Events, exhibitions, seminars

However, the most influential communication method is personal contact, which is the purpose of the yearly STAKES event, HEALTH-SOC (TERVE-SOS). It is a three-day cavalcade of seminars, social events, exhibitions, and discussions for some 10,000 people interested in social and health services, research, and development. The SOTKA team has actively participated in the event, arranging SOTKA demonstrations and a special feedback session for SOTKA clients (Hakkarainen A. 1998c, Lounamaa A. and Hakkarainen A. 1998).

In STAKES SOTKA comes under the Unit of Statistics and Registers, and is a special focal point for its Front Office for client service. The Front Office gives direct advice by telephone, e-mail, fax, and mail, participates in exhibitions, works in sales promotion for STAKES' statistical products (electronic & paper), and arranges seminars on statistics and registers.

The SOTKA network .

The campaign called *SOTKA for All Municipalities* in 1997 started the building of a network between the SOTKA team and the database users. The Ministry of Social Affairs and Health offered the SOTKA license to the municipalities free of charge and the SOTKA team at STAKES arranged a training tour around the country. In the first year 15 seminars were arranged all over the country by a three-member team. This tour reached about 300 potential users.

The seminars started with a description of the statistical reform (1994) and its principles. SOTKA's content was described as well as the practical, scientific, and ideological criteria why just these variables were selected for the database. A graphic presentation of central policy issues was produced for the participating municipalities. The technical details concerning the installation of the program and telecommunications accessories were given followed by a demonstration.

A network of contact people including 370 local officials was built around SOTKA. This number is bigger than the number of SOTKA licences in the municipalities so local officers want to be informed. The aim of the network is to support, guide, and inform the SOTKA users and to get feedback for SOTKA's developers. The support network has proven to be valuable for the development of the whole statistical system but it has also been a pleasant and encouraging experience as there is a spirit of cooperation.

A newsletter was created by the SOTKA team that is sent to the local contacts3 to 4 times per year. The team arranges statistical and computer training 4 to 10 times per year free of charge. About 150 members of the network were seen face to face last year. This service has become very popular among the local statistical officers (Lounamaa A. and Arajärvi E. 1998). The upkeep and development of the network service takes about two person years per year.

Reading statistics is like reading poems they are formal, concise, and full of meanings. A circle of devotees will help the interpretation.

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PLANEC - Information based care for elderly people

by Marja Vaarama and Lic Päivi Voutilainen

Abstract

The article describes the development process of PLANEC Performance Management System that was carried out by launching a European research project during 1996 and 1998. The task of the PLANEC system is to serve as a tool for planning, monitoring and evaluation of the care of the elderly to achieve a balance of care by matching needs to resources. The theoretical frame, structure of the system as well as thorough validation process are discussed in detail.

Introduction

Demands to secure the greatest possible improvement in performance of public financed social and health care of the elderly through available resources are strong in all European countries. This demand is somewhat more difficult to meet in urban areas with higher proportion of elderly people and more fragmented provision of care. Improving the efficiency of the elderly care services delivered challenges planners, managers as well as providers to base the decisions on the evident facts. These demands raise the need for information systems to facilitate the decision making process, for implementing the tools developed to change the practice and thus deliver the best possible care to the elderly, carefully considering the equity, costs, goal achievement and quality of services delivered.

An advanced performance management covers monitoring, evaluation and planning of care, as well as co-ordination of the provision. These areas form the basis when developing tools to facilitate the decision making process. It is obvious that the need for broad and refined information systems on the care of the elderly exist. Meeting the need of facilitating better-informed decisions requires both client level and strategic level management systems with sophisticated measures. To address the client needs and desires there is also a need for more transparent planning and evaluation procedures, where the care plans and priorities are subjected to the democratic control by public discussion. These were the reasons for developing the PLANEC Performance Management System targeted at health and social care planners, managers and providers throughout Europe. The launch of a European research project began the development during 1996 and 1998. The PLANEC software application consists of a multidimensional,

http://www.ehto.be/
ht_projects/planec

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relational database with flexible aggregation functionality, standard PLANEC performance indicators and planning models, standard analyses and reports as well as facilities for optional analyses and reporting. Also www-links for exporting and importing data exist.

The PLANEC approach to performance evaluation

The task of the PLANEC system is to serve as a tool for planning, monitoring and evaluation of care to achieve a balance of care by matching needs to resources. Thus, the core issues that PLANEC is dealing with are the management and the performance of care, as well as links between them. A theoretical approach encapsulating relevant dimensions of the performance of care systems in one theoretical framework is the production of the welfare (PoW) model (see Davies and Knapp 1981;1988, Knapp 1984; 1995). It was also the approach for the PLANEC research. Vaarama (1996) discusses the way that the PoW model was implemented in PLANEC in more detail. The production of the welfare approach is a summary of the complex linkages between policy goals and practices, services and achievements and the (material) resource and (immaterial) non-resource inputs that make them possible. (Knapp 1984; 1995). The approach gives a framework for distinguishing the key elements in the welfare and health services production and a framework on which to hang an evaluation of the performance of the care system, which is the intended core task of the PLANEC application. The way how the production of welfare approach was serving as a framework in the PLANEC development can be clarified by using Vaarama's (1995, 82) model of macro system-level performance evaluation of public care services. (Figure 1)

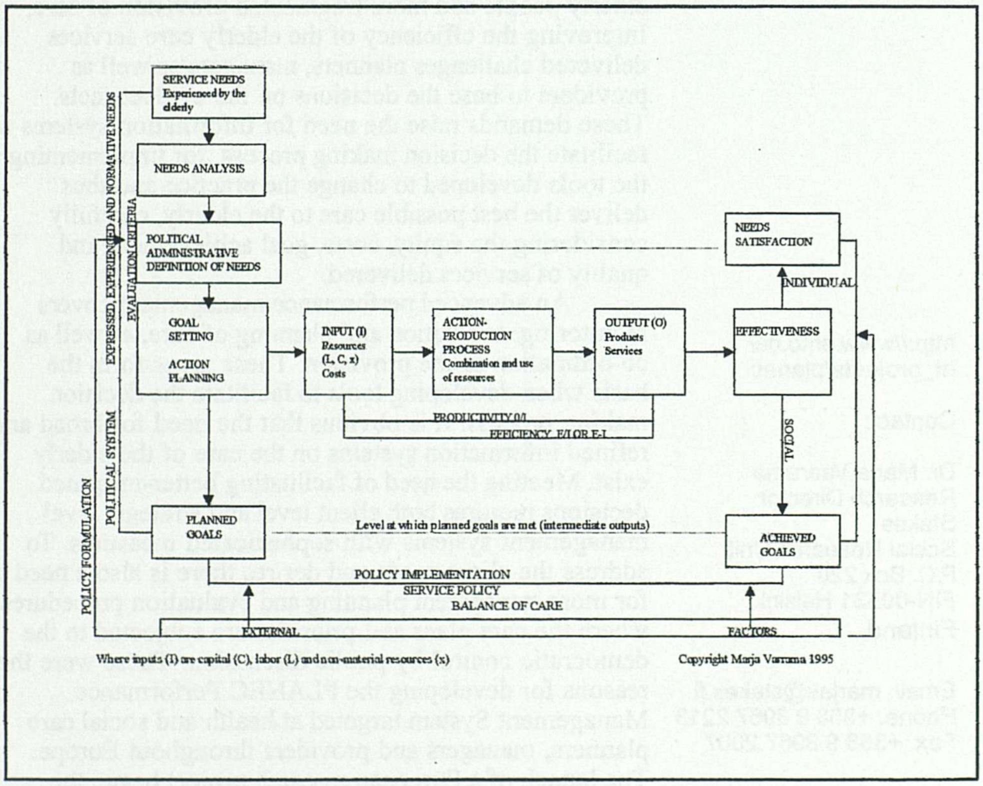

Figure 1. Theoretical framework for performance evaluation of the public care system (c.f. Drummond et al 1987)

First, the model describes the basic elements of production of welfare in public (financed) care system. Second, it describes the linkages between policy goals, welfare production and performance evaluation. Third, the model clarifies the concept of efficiency and levels of efficiency measuring.

The PLANEC project description

The PLANEC project involved five European countries: Finland (co-ordinator), Germany, Netherlands, Spain and United Kingdom. The goal of the project was to develop an intelligent software tool for:

1. strategic care management of the elderly
2. research of the care systems and their performance.

In the development process the following underlying assumptions were taken into account:

- the goal of the project was a very pragmatic one: to develop a software to be used in everyday practice
- the application development was to be based on thorough information on user needs
- the application was to be user-friendly
- the development was to be built on sound scientific base.

Various methodological approaches and techniques were employed in the research and development process. The IV Framework Programme/ Health Telematics of the European Commission mainly funded the project. (Vaarama et al 1999b)

The project was carried out in close collaboration with the end-user representatives in 5 project countries. The interaction with the potential end-users actually started with an extensive survey. The diversity of welfare state models represented by the project countries together with the iterative development process was to ensure a successful implementation in the European context. The balance between standardisation (that gives the widest benefits), flexibility and attractiveness (that ensures the market take-up) were addressed in the design and development of the demonstrator. The functional specification of the system was carried out using object oriented analyses and modelling techniques (OOA/M), again involving intensive interaction with the user panels. Scientific research provided the necessary input in terms of performance indicators and scenario models incorporated in the demonstrator. A high level of user involvement was maintained during the system design and development stages. This user-driven approach culminated in the validation of the demonstrator, where the standardised validation methods of Megataq and SUMI were employed. (Vaarama et. al 1999b).

The outcomes of the project were:

1. a validated prototype application
2. the validated and scientifically underpinned standard PLANEC performance indicators
3. a client-level Target-Efficiency Model prototype
4. an iterative model of application design, development and evaluation. (Vaarama et al. 1999b).

The structure of PLANEC

The PLANEC system consists of three major modules:

PLANEC database
PLANEC analyses and indicators
PLANEC models.

PLANEC database is a tool for collecting, storing and retrieving data about elder care services. It includes 13 different classifications for standardisation of data collection. The database includes:

1. database where data is stored
2. the data set configuration where the user can choose the data they want to use
3. aggregation module where data is prepared and aggregated to a single database
4. data exchanging facilities where data can be taken in and out of the application
5. data viewing/editing module.

Technically the PLANEC database is a relational multidimensional database for storing and retrieving data. The database uses standard database tools (MS Access). The aggregation module has been developed within the project.

PLANEC analyses and indicators consists of analyses and indicators addressing the performance of elder care. The PLANEC analyses include a set of predefined indicators for monitoring and evaluating the effectiveness, economy and efficiency of the services. They have been validated for their reliability and validity by expert evaluations, and for their utility and relevance by the national validators representing potential end-users of PLANEC.

PLANEC models are intended for use in planning of the services for the elderly and simulation of the performance of alternative care models. The essential strategy of PLANEC as a planning tool is the use of scenarios. The care system is divided into subsystems, which can be analysed in detail. In PLANEC, the following subsystems are included: the service needs, the service systems, the service provided, the performance factors of services both in actual and in model or target worlds. (Vaarama et. al 1999a; 1999b)

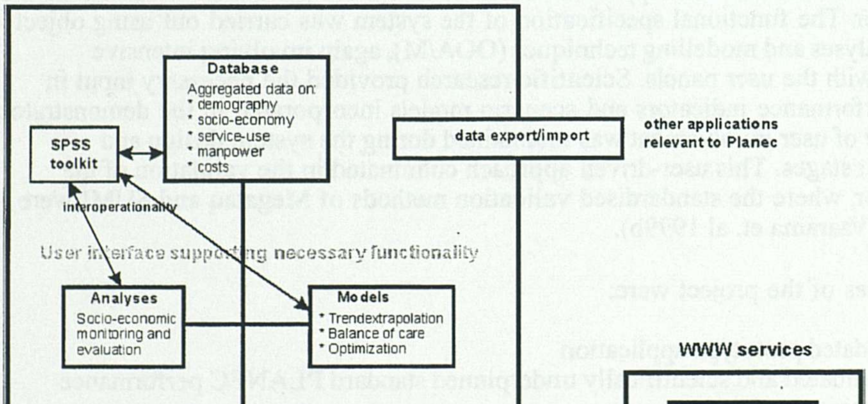

Figure 2. PLANEC application in 32-bit Windows environment.

Research on the functional specification of the PLANEC system

The approach of PLANEC is to devise a flexible and modular system that will be used by a very wide range of potential users. To accomplish the task of the functional specification of the PLANEC system that met the different needs of various users, the Object Modelling methodology was choosen as the main tool, and it was applied in an iterative process involving the researchers, software engineers and users. Extensive user-research started the process of system specification. First using the OOA/M, national object models for the activities involved in the care of the elderly were created together with the care managers and other practitioners. From these, the project consortium integrated a European Consolidated Model.

To develop performance measures for the PLANEC application some key indicators for monitoring, evaluation and comparisons of elder care were to be created. The concept and development of these indicators was based on the theoretical framework of production of welfare. According to the model, the important items for performance evaluation are (Knapp 1995):

1. the resource inputs (staff, capital, consumables)
2. the costs in monetary terms
3. non-material resources
4. intermediate outcomes of care, (service types, volumes, throughput, quality of care)
5. final outcomes of care (welfare and health effects).

The preliminary listing of the indicators was made in the course of the Functional Modelling of the PLANEC system. Those already validated either in research or practise were included in the first PLANEC-prototype for testing by researchers and users. Of those still at an idea stage or in need of adaptations, further research was performed. The indicators were selected and new ones piloted, and implemented in the demonstrator. The final validation of the indicators was performed in two stages: as a part of demonstrator validation, and as an expert evaluation (Vaarama et al 1999a).

Development of the prototype

The system design and demonstrator development OOA and OOM process was connected to the model of iterative application development mode, where the design, development and iterations follow each other in a cyclic process. All iterations were made together with the end-user representives in each project country. The results of user iterations suggested that the core tasks of PLANEC should be to support the user to:

- Define target for care provision
- Monitor developments
- Evaluate performance
- Analyse need/demand
- Analyse quantitative output
- Analyse qualitative output
- Analyse material input
- Analyse non-material input
- Analyse effectiveness
- Analyse productivity
- Analyse economy
- Analyse efficiency
- Analyse equity

- Identify imbalances / mismatches
- Identify efficiencies / inefficiencies
- Produce projections of future demand
- Evaluate against state of the art
- Report developments.

Bearing in mind the need of an intuitive application structure and also the rapidly growing use of the Internet, *Internet Explorer* was selected as the new application environment. In the demonstrator the application structure is based on the Internet concept of a number of interlinked documents that encapsulate parts of the application functionality. This means that we separated different operations into different modules giving the user 'tools' within the application to perform specific tasks and the user has a button bar for selecting the documents he needs for each task. Because the Internet Explorer is used as the application environment it is very straightforward to extend parts of the application functionality to remote servers in the future. In the demonstrator this possibility is illustrated by implementing the upload/download of PLANEC export files on the PLANEC WWW server. (Vaarama et al 1999b)

The PLANEC application has been implemented using *Microsoft Visual Basic* to create *ActiveX* components that run under *Internet Explorer 4.0*. In principle this kind of technical solution combines the flexibility of the Internet environment with the effectiveness of the Rapid Application Development tool like Visual Basic. Even if this technical solution is at the moment restricted to Windows 95/98/NTenvironments, it offers a lot of possibilities for Internet Data Access and Software distribution. The reporting functionality of the PLANEC application is implemented by using *SPSS 8.0* report viewer which offers a lot of possibilities for displaying tables and graphics that are modifiable by the user at runtime. So generic technology and existing components have been used whenever appropriate to increase efficiency in application development. The application development was made in a stepwise process, where several prototypes were developed and evaluated. The first prototype was completed and evaluated in spring-summer 1997, the demo of the second prototype in October 1997, a partial second prototype in January 1998, the completed second prototype in April-May 1998, and the demonstrator in August-November 1998 (Vaarama et al 1999b).

Validation process

In addition to the ongoing evaluation as a part of iterative application development process, a total of 34 end-users from Finland, Germany, Netherlands, Spain and UK validated the application in addition to the PLANEC project team. They represented different actor perspectives and validated the demonstrator in the period from August to November 1998. The criteria to invite the validators were that they were to represent a good sample of the potential end-users of various types in each country. The Megataq approach was used as a validation methodology. Six specific questionnaires were developed to measure the functionality of PLANEC and a standardised questionnaire (SUMI) was used to measure the user friendliness and appearance in a way that can be compared with validations of other applications. Specificattention was paid to comparing the 'presently available data processing tools' with the functionality offered by PLANEC and to cost effectiveness. The validation criteria were the usability, practicability, relevance and effectiveness of the PLANEC-system. (Vaarama et al 1999a)

The validation results were in general very positive. Starting the application and navigating through different components caused no problems. The structure of the PLANEC Database met the needs of the respondents. The dimensions and service variables in the database and its flexibility were evaluated as useful, clear and complete, meeting the requirements of the respondents fairly well. However, selecting the right dataset properties to get certain results was difficult for some of the respondents (Vaarama et al 1999b).

In general, most PLANEC indicators and analyses were evaluated as useful. Most respondents expect that they would use many of these in their future work. Some slightly different responses were found to be related to the professional backgrounds of different respondents. The medically specific variables, indicators and analyses were evaluated positively by respondents working in the medical sector. The other respondents evaluated these variables, indicators and analyses as less relevant for monitoring and evaluation in their own area of elder care. Also the PLANEC scenario models were evaluated as useful, relevant and efficient tools for practical MEP. The functionality, however, needs refinements and customization before entering the markets (Vaarama et al 1999a).

In general, the structure of the application and the user interface were evaluated as clear. Most respondents reported few problems in navigating through the application by the selection trees, with the button functions, or to locate the reports they wanted to produce. Most respondents evaluated the SPSS output as 'good', but the visual quality of graphs was often evaluated as partially satisfactory. Adjusting the layout of graphs in SPSS was evaluated as difficult and the speed of calculating was reported to be only partially sufficient (often due to the low performance of the computer used). Almost half of the respondents reported that the Help and the User manual were only partially clear (Vaarama et al 1999a).

Comparing the functionality of present tools with those offered by PLANEC show that the demonstrator was more frequently better than the presently available tools on all aspects like numbers of indicators, tables and graphs, correct calculations, visual quality, ease of use and the time needed to make outputs. Evaluation from the Cost-Effectiveness perspective show that by far most respondents expected time savings from using PLANEC instead of their presently available tools for most tasks. Also an extensive external evaluation by experts was an ongoing affair in PLANEC (Vaarama et al 1999a).

Results dissemination and further development of the system

The three main ways of exploiting the results of the PLANEC project are:

(1) development of final product,
(2) marketing and selling the product and
(3) the consultancy, training, maintenance and other services around PLANEC.

For the product development, selected partners of the current consortium established a company for joint exploitation in May 1999. The PLANEC software will be on sale in 2000. The selling and marketing is planned to be European wide and SPSS International is planned to have a lead role in this. The training, consultancy and other expert services will offer new opportunities for Universities, Research Institutes and Consultancy Agencies in all countries taking the PLANEC for implementation. The maintenance services offers jobs for the software houses, and the data collection will provide new jobs for the data providers in various countries.

Overall, based on careful research and design the project has developed a sophisticated Performance Management Tool. Currently, there exist plans for developing tools to extend and deepen the PLANEC-approach further.

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