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This paper represents the collaboration between the Cancer Council NSW, Greenacres, the Disability Sector, and the University of Wollongong (UOW) who came together through a UOW Community Engagement Grant (2010) to develop a series of skin cancer prevention resources for mildly intellectually disabled (MID) people. By interviewing 84 MID people from Greenacres, a local employer of people with mild intellectual disabilities, we report on their skin cancer prevention behaviours after our intervention with The Spot Pack, a kit designed to encourage self-examination for skin cancer spots. We found that nearly 20% of the respondents checked themselves for skin cancer spots for the first time as a result of the being given the kit. This project has several implications for both theory and practice when dealing with such vulnerable groups, with the most important being the role of an integrated approach, with tangible resources backed by a structured approach to educating the group.

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Helping People with Mild Intellectual Disabilities (MID) Check for Skin Cancers: An Intervention

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Abstract

This paper represents the collaboration between the Cancer Council NSW, Greenacres, the Disability Sector, and the University of Wollongong (UOW) who came together through a UOW Community Engagement Grant (2010) to develop a series of skin cancer prevention resources for mildly intellectually disabled (MID) people. By interviewing 84 MID people from Greenacres, a local employer of people with mild intellectual disabilities, we report on their skin cancer prevention behaviours after our intervention with The Spot Pack, a kit designed to encourage self-examination for skin cancer spots. We found that nearly 20% of the respondents checked themselves for skin cancer spots for the first time as a result of the being given the kit. This project has several implications for both theory and practice when dealing with such vulnerable groups, with the most important being the role of an integrated approach, with tangible resources backed by a structured approach to educating the group.

Keywords: intervention, skin cancer prevention, mild intellectual disability

Track: Social marketing

1.0 Background

We know little of the skin cancer-related prevention and screening behaviours of people with mild intellectual disabilities. This is surprising as Patja, Eero and Iivanainen (2001) suggest that 1% of western societies populations have an intellectual disability and are more adversely affected by cancer outcomes than the general population. Similarly, Castell (2008) identifies using ABS data (2003) that 79,100 Australians have a mild intellectual disability. Within the literature this gap is evident by examining Kasparian, McLoone and Meiser's (2009) wide ranging literature review of studies focussing on specific groups such as school students to broader community based cross-sectional studies of the population, but no studies were reviewed focussing on people with a mild intellectual disability (MID).

While many studies have examined whether or not sun safe messages are getting through to the general population, few studies have examined this with in the MID population. Are they engaging with the sun protection messages that many dedicated non-profits have spent considerable time and financial resources in promoting to the wider community? Our paper focuses on this point and the effectiveness of our intervention designed to promote self-checking for skin cancer spots.

In our case, it was a Community Volunteer with Cancer Council, NSW, whose role was to spread the sun safe message to various disability groups, seminars spreading the skin cancer prevention message *Slip, Slop, Slap* who brought this project to life. Having completed an undergraduate degree in Marketing at UOW she had serious concerns regarding the comprehensibility of much of the literature given out at her seminars to people with mild intellectual disability. As the Cancer Council is dedicated to the defeat of cancer and has the broadest reach of any cancer organisation in New South Wales, she saw a need for improving its information resources. Specifically, adapting their existing messages so that they were more comprehensible to an audience that has learning difficulties resulting in low levels of

literacy, and impaired learning and cognitive processes when compared to the general population.

Ouellette-Kuntz (2005) defines intellectual disability as a *significant* limitation in both the intellectual functioning and conceptual, social and practical adaptive skills originating before the age of 18, whereas in our population of interest the intellectual disability was not *significant* but *mild*.

A first step in the process was the formation of a formal Community Reference Group where several community sector groups joined together (The Disability Trust, NSW Council for Intellectual Disabilities, ADHC, Greenacres) with a clear purpose to discuss the best ways of developing resources that could be used by their clients or to assist their clients in relation to all things cancer. By approaching researchers from UOW, the opportunity to apply for a UOW Community Engagement Grant arose where the grant application focussed on developing an introductory guide on 'How to Provide Complex Information in an Accessible Format' for people with mild intellectual disabilities and those with learning difficulties. Full of enthusiasm the researchers thought that this 'how to' guide would be a valuable resource for those promoting health messages particularly within the disability sector where the dissemination of complex information provides ongoing challenges for parents, carers and service providers.

We learned quickly that the term 'mildly intellectually disabled' has various meanings with no established definition used by all of the community groups. Unfortunately for the academic researchers, the reality of the situation became abundantly clear with many of our partner organizations suggesting that we were very naïve in trying to develop a prescriptive approach to communicating health messages to a population with such varied learning and cognitive issues.

While hearing and noting their concerns, we undertook a review the literature to determine the state of play in the area. In one of the few studies in the area of intellectual disability and health interventions, Greenwood et al (2014) stated that while evidence-based health education and health promotion interventions are important tools for reducing health disparities there is a paucity of data regarding what constitutes effective health promotion and education in adults with intellectual disability. To our surprise and consternation we found very little in the way of an accepted methodology or a set of marketing communication theories that have been utilised to design communication resources and health interventions for people with intellectual disabilities. So to overcome these methodological and theoretical limitations we decided to go back to basics and adopt a transformative research approach by including the target audience in the research design process. To provide structure we used the social marketing planning process advocated by Kotler, Roberto and Lee (2002) in their text *Social Marketing: Improving the Quality of Life*, which begins with (1) conducting a situation analysis, (2) selecting a target audience, (3) set objectives and goals, (4) analyse target audiences and the competition, (5) develop marketing strategies – the 4p's and (6) develop a plan for evaluation and monitoring. By doing so we focussed on the behaviour change aspects of the project, and had an opportunity for direct feedback from our MID co-researchers, rather than just focussing on the communication challenges faced by the target audience. The following sections will briefly outline key elements of our research process and the reasoning behind it.

2.0 The Research Process

It was decided early on by all the participant groups who formed the initial committee (Cancer Council, UOW, Greenacres, Disability Trust) that the relevant social issue was the prevention of cancer through early diagnosis and self-examination, and that the best way to proceed was to form a 5 person Reference Focus Group (RFG) consisting of people with mild intellectual disabilities from the various participating Disability Sector client base. The RFG would then become “co-researchers” in the project. Their first task would be to determine the effectiveness of the existing Cancer Council booklets and information, allowing us an opportunity to understand our target audiences comprehension capabilities first hand. This approach is advocated by Walmsley (2004) who refers to it as inclusive learning disability research where the involvement of users better informs practice and adds value. Over the projects life (3 years and multiple meetings) we indeed learned some valuable lessons which will definitely inform practice and add value to anyone engaging in similar projects with MID people. One of the key *learnings* was the importance of building rapport, a very informal approach was taken with the RFG members who were given a large degree of autonomy in how they would like our meetings and research activities to run, and how often they would like to meet. We discussed the types of activities they may be involved in as part of the group e.g., reviewing resources, providing feedback and ‘driving’ the resources to be developed where we developed a visual one thumb, two thumb, three thumb ups/a one thumb, two thumb, three thumbs down approach to what works and what doesn’t work.

In terms of project specifics, we had to determine which cancers to focus upon for the project, and as summer was approaching the RFG decided upon *skin cancer awareness* with the intention to have resources available for use over summer. So to begin the project the effectiveness of the existing Cancer Council SunSmart, Save your Skin, 19 page booklet was reviewed by the RFG focus group, immediately it was apparent that the booklet was too information rich, too full of jargon, with too many messages for the focus group to comprehend. As it had been decided that the bulk of the resource development will be driven by the RFG members themselves, the group spent a session reviewing current resources and using a variety of resources to develop their own Cancer Council Sun Safe messages. There were no rules - the group were encouraged to use whatever they wanted (including drawing and writing materials, and photos and symbols from current Cancer Council brochures etc) to develop a resource that delivered their message in a way that they could easily describe to their friends with MID. At the end of the exercise, each participant had an opportunity to present their message. The presentations of their messages provided the researchers with valuable information to consider for developing draft Cancer Council resources for consideration by Reference and focus Group members at the meetings to follow.

3.0 Implementing the Intervention

After a considerable period of time what was eventually developed by the reference focus group was a move away from a new brochure that was easier to read and comprehend to a more comprehensive and interactive approach, where they developed the Spot Pack as an intervention to be given to MID people. It consisted of a hand held mirror, a removable sticker with a *check that spot* message which could be placed on a bathroom mirror and a Spot Book. The spot book allowed the user to mark on a body outline the position of any suspicious spots which could then be shown to their doctor for further examination. The target audience were clients of Greenacres, a registered disability service provider. Importantly, Disability service providers are legally required to ensure all participants within their services

understand their rights and responsibilities in regards to Privacy, Dignity and Confidentiality. All the participants were over 18 and provided their own informed consent. The volunteers read a very simplified consent form in a format that they are accustomed to (with previous experience) and signed it. Such simplified consent forms enabled participants to have a clear understanding of their roles, and their rights and options for withdrawal from the research. Finally, the MID participants at Greenacres are accustomed to making their own life choices with many belonging to self-advocacy groups. The research was also approved by the UOW Ethics Committee who had initial concerns as to the cognitive ability of the group, and whether or not the use of any fear appeals would cause emotional distress but were satisfied by a letter of support from Greenacres.

The Spot Pack was given to 84 MID employees of Greenacres in late November 2013 and the respondents were interviewed in two separate sessions (two days apart) at their place of work. As well as being given the Spot pack at a formal meeting prior to the interviews, they were also shown how to check themselves with the mirror and act as *Spot Detectives* looking for any suspicious spots which would be recorded in their own Spot Book. In late February, at the end of summer the interviews were conducted using a questionnaire that was developed with the assistance of the RFG. It had the following sections (1)summer sun behaviours, (2) do you remember getting the Spot pack, (3) your spot checking behaviour over summer, (4) action if a spot found, (5) did you use the mirror, the sticker, (6) melanoma awareness, and (7) recall of sun safe advertising over summer, (8) respondent information. In the following section, we present the results of this intervention aimed promoting self-examination behaviours and encouraging visits to their doctor (GP) when in doubt.

4. Results

For our analysis we sought descriptive statistics relating to specific behaviours and attitudes. As part of the data analysis we conducted between group analysis (ANOVA) where we sought to see if there were relationships amongst key variables such as level of intellectual disability, living independently, attitude towards getting a sun tan etc. To our surprise there were none evident. Here are some of the key descriptives, we had 84 respondents, male n = 49 (57%), female n = 37 (43%). Ages: 18 to 25 = 22.1%, 26 to 35 = 37.2%, 36 to 45 = 15.1%, 46 to 55 = 16.3%, 56 to 65 = 5.8 %, Did not know = 2.3%. Their level of mild intellectual disability was assessed in the following manner noting that while all respondents are viewed as having a mild intellectual disability, they are not a homogenous group. To capture differences within the group their level of *mild* intellectually disability was measured by the level of their dependency on additional support in performing their work tasks at Greenacres. This was assessed by their manager and reflects their judgement: Highly Independent: n = 11 (13%), Moderately Dependent: n = 49 (58%), Low dependency: n = 24 (29%). We also found that 72.1% lived at home with their family to 28.9% who did not.

Table 1: Sun Safe Behaviours of MID people

Over summer did you spend much time outside in the sun?	Not at all	Sometimes	A lot
	10.5%	47.7%	39.5%
When you went outside in the sun how often did you put on Sunscreen?	Never	Sometimes	Always
	16.3%	33.7%	47.7%
When you went outside in the sun how often did you put on a Hat?	Never	Sometimes	Always
	16.3%	27.9%	54.7%

	Never	Sometimes	Always
When you went outside in the sun how often did you put on Sunglasses?	23.3%	23.3%	52.4%
When you went outside in the sun how often did you put on a Long sleeve shirt?	61.6%	24.4%	11.6%

Table 2: Spot checking behaviours of MID people after the Intervention

Was it the first time you ever checked yourself for spots?	Yes 19.8%	No 80.2%
How often do you check yourself for spots?	After every shower	26.7%
	Once a week	17.4%
	Once a month	10.5%
	Once a year	1.2%
	Never	40.7%
How did you check yourself?	By yourself 30.2%, With a Family member 25.6%, with a Carer 4.7%, Doctor 3.5%.	

5.0 Discussion, conclusion and future research

The primary purpose of the study was to promote skin cancer checking behaviour amongst a vulnerable community and the secondary purpose was to ascertain whether or not they were engaging with the sun safe message of Slip, Slop, Slap which had been promoted by the Cancer council for many years. In terms of Spot Checking behaviour, with nearly 20% of participants checking themselves for the first time and 44% either checking themselves after every shower or weekly, the intervention has been positive. Interpreting the results, it seems that the message Slip, Slop, Slap has been taken to heart by the participants in the study, with the majority of respondents putting on sunscreen, a hat, and sunglasses. Long sleeve shirts however are not popular as a preventative measure. While these results are encouraging they need to be considered cautiously in terms of their implications for practice, as space restrictions limit presenting all of the results, the sticker, booklet and mirror were not a success, the sticker was not effective in reminding people to check for spots, the book hardly used and not taken to their doctor, and the mirror rarely used, but rather the process of taking a Spot Pack home triggered discussion and behaviour change amongst family members. From a researcher perspective, including the target population in the study was beneficial as it allowed us to better understand their abilities, however there were considerable trade-offs in terms of time taken to complete the project and efficiency as research meetings could only be done outside work hours. Social desirability responses were an issue at times as well as limited recall if the meetings were spread out over a period of weeks.

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