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Coproduction can lead to healthy living for adults with intellectual disability

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Healthy living: a health promotion program for adults with intellectual disability

Abstract

Background: Adults with intellectual disability are more likely to experience a range of physical and mental health problems in comparison to the general population. However with access to appropriate health care and promotion, many of these health problems can be prevented.

Objective: To explore the perspectives of stakeholders of a health promotion program established for adults with intellectual disability.

Methods: Semi-structured interviews were conducted with 12 stakeholders of a health promotion program. Stakeholders included adults with intellectual disability (n=6), their support persons (n=4) and program presenters (n=2). Adults with intellectual disability included three males and three females with a mean age of 45.5 years (range 37-51 years). Interviews were digitally recorded and transcribed verbatim. Transcripts were analysed using thematic analysis.

Results: Four main themes emerged from the data.The first theme highlights the positive feedback all stakeholders, especially adults with intellectual disability, had for the program and the second focuses on suggestions for changes to improve it. The third and final themes explore how having input from adults with intellectual disability and their support persons, who have a unique understanding of their needs, could be better incorporated into the development of the program.

*Conclusions***:** This health promotion program has been well received by people with intellectual disability when incorporated into their weekly social club meetings**.** With encouragement and training, people with intellectual disability and their support workers could be more involved in the development of the program to ensure it is relevant to their needs.

Introduction

Approximately 3% of Australians live with an intellectual disability.[1] This group experiences substantial health disparity compared with the general population including poor access to quality healthcare services and insufficient health promotion.[2] As a result they experience poorer health and have a shorter life expectancy.[3] Health problems include behavioural and mental health issues, unrecognised vision and hearing problems, epilepsy, skin conditions, poor oral health and respiratory conditions.[2] Socio-economic disadvantage, and the extent to which the discriminatory cultural and social attitudes toward disability serve to restrict the access of disabled people to living conditions that are associated with better health and to timely and effective health care, are considered major contributors to their poor health.[4] With proper healthcare, education and a healthy lifestyle many of the health problems experienced by people with intellectual disability can be prevented.[5]

In order to avert preventable health problems and improve the health of people with intellectual disability, health promotion programs are needed. People with intellectual disability are not involved in health promotion activities as much as the general population[3] and there are very few health promotion programs available specifically for this population. As Rimmer and Rowland[6] suggest, it is essential for health promotion professionals to be aware of the disparity between people with disability and the general population to reduce barriers for them to engage in health promotion practices. Challenging the notion that people with a disability should naturally have worse health than their peers without a disability, a resource produced by the Victorian State Department of Health in Australia identifies the underlying drivers of the poor health of people with a disability and provides guidance to address them.[7] They also emphasise the importance of involving people with a disability in the development and delivery of programs and empowering people with disability to understand their choices and related health behaviours.

Kuijken et al.[5] is one of the first studies to explore the views of people with intellectual disability about living healthy and found there was a need for adapted programs. A health promotion program run by members of the developmental disability community in collaboration with academic researchers, using community-based participatory research methods, was shown to result in healthier lifestyles of the participants.[8] Terms such as 'participatory research', 'emancipatory research' and 'inclusive research' are becoming more apparent in the disability health literature indicating that health programs are gradually becoming inclusive.[9,10]

Co-production is a form of inclusiveness where service users are involved in all stages of the development and delivery of a service.[11] Co-production in health services allows health consumers to gain a stronger role and status rather than passively receiving what the experts or service providers offer. Those who use a service are best placed to help design it and past research demonstrates the effectiveness of co-production applied to a range of services.[12-14] Other benefits include value for money, improved social capital, increased practical skills for service users and improved health outcomes as a result of their contribution to the prevention agenda in health and social care.[15] Roberts et al.[14] demonstrated co-production empowers users with learning disability and can lead to the development of many practical resources. Like individuals within the general population, people with intellectual disability, who are the experts in their lived experience, have the right to be involved in the development of services.

Healthy Living is a health promotion program developed in 2012 by three health organisations for people with intellectual disability in an Australian city. At the time of this research the program ran fortnightly for members of a weekly social club and offered informative sessions on living a healthy lifestyle. Health professionals from different professions presented each session and members were supported to participate by workers of a local disability support and advocacy organisation that

facilitated the club meetings. In this article, we aim to evaluate the Healthy Living Program and explore the following research questions:

1. What did stakeholders think of the program?
2. How satisfied were stakeholders with their level of involvement in the program and would they like this to change?
3. What did the stakeholders think of others' level of involvement in the program?
4. What improvements could be made to the program?

Methods

Study design

This was a qualitative research project, undertaken in 2016, involving semi-structured interviews with stakeholders of the Healthy Living program, i.e.social club members with intellectual disability, support persons of this club and presenters of the Healthy Living program. Ethics was approved by The Behavioural and Social Sciences Ethical Review Committee of The University of Queensland (Approval Number 2014001547).

Participant Recruitment

Club members (n=6). Club members (P1-P6) consisted of attendees of a weekly social club who attended Healthy Living sessions. AA attended a Healthy Living session and introduced the research project to everyone. Club members who showed interest in the project were provided with a participant information sheet which was either explained or read out to the club member. If participants were unable to consent, a substitute decision maker signed the consent form and the participant with intellectual disability provided assent. There was no formal assessment of capacity

to consent for people with intellectual disability: this was determined on the advice of their support persons. Club members consisted of three males and three females with a mean age of 45.5 years (Range = 37-51 years).

Support Persons (n=4). Support persons included three female support workers from a community support and advocacy organisation (S1-S3) and one male volunteer (V1). The support workers are paid workers of a support organisation but not carers of the individual club members.

Presenters (n=2). Presenters included a previous female presenter of a session for oral health (Pr1) and a male social worker who is one of the co-organisers of the Healthy Living program (Pr2). Presenter 1 was recommended to participate in the evaluation by Presenter 2.

Data collection

Interview questions were in relation to how participants felt about the Healthy Living program and delved into their thoughts, ideas and suggestions regarding past and future sessions. The semi-structured interview questions were different for the club members and the rest of the study participants. The interview schedules had been reviewed by a person with intellectual disability and other researchers during development. Slight modifications were made to the interview questions for both groups depending on the outcome of the first interviews, for example, by changing words or moving questions around. The final interview schedules are included in the Appendix.

The interviews were conducted at the social club venue by AA who had attended the club once prior to conducting interviews in order that club members and support persons might feel more comfortable with her. One of the two presenters interviewed facilitated all the healthy living sessions and consequently was also known to AA prior to the interview. Both people with

intellectual disability and support persons were interviewed during or after the social club meetings. Presenters were interviewed at a location and time of their choice. Interviews took an average of 10 minutes (Range = 5-20 minutes).

Data analysis

Interviews were digitally recorded and transcribed verbatim. NVivo software (Version 10; QSR International, 2012) was used to manage and organise qualitative data. Transcripts were analysed using thematic analysis[16] by the first author (AA). After familiarising herself with the transcipts, AA generated the initial codes and searched for themes within the data. As described by Braun and Clarke,[16] a theme captures something important in the data in relation to the research question and represents some level of patterned response or meaning within the data set. LM checked the themes to ensure consistency in interpretation. Any disagreements were resolved through discussion.

Results

Initially, only half of the club members had a clear understanding of the purpose of the Healthy Living sessions noting key terms such as “trying to stay healthy” (P2), “proper diet, fruit and exercise and proper accommodation and everything like that” (P5), “get our medical ... things seen to … making sure that we’re getting everything that we need to eat” (P6). They understood that the presenters of the Healthy Living program were people who “give you a lot of advice on how to live healthy” (P6). The other half of the club members when asked what they thought about the Healthy Living sessions talked about the social club aspect where morning tea is always provided: “It means eating lots of fruit, enjoying company ... being with friends” (P1), “Well morning tea is fairly healthy. Fruit and bits and pieces. That’s about it” (P3). With these club members, questions that were

specific to the Healthy Living talks were asked in order to lead the interview back to the Healthy Living program.

"I love it, I love it, I love it" (P2)

When specifically asked about the program, all club members stated they enjoyed the Healthy Living sessions. Generally members liked to be involved in the sessions and appreciated the need for the sessions. When asked which session they enjoyed the most, one member answered "they're all good" (P1) while another member gave a specific session "learning about when to call a doctor" (P6). The members had awareness of health, "Health is important isn't it" (P5), and the Healthy Living sessions had impacted on their lives, "I'm starting to get active … and getting around the community" (P5). Another club member also talked about being "fresh mentally" (P2).
The support workers and presenters believed the program to be "definitely something that's beneficial" (S2) as they described it as "fantastic" (S3), "wonderful" (Pr1) and "highlight of my week" (Pr2).

> "I think … it's great for … these guys to get some information that they may not have … had prior … or they may not have access to ... and they may have been either misinformed or not educated on it so I think it's a wonderful program." (S1)

> "Hopefully bit by bit we'll try and improve their ... health and wellbeing because you know where they live in hostels they don't have the opportunity to eat properly, to make them aware and you know how to get the best out of their appointments with doctors so … I think it's been an incredible education for our residents so ... long may it go on." (S3)

The oral health session seemed to be the most successful session of the program with a mobile dental clinic available for the club members.

> "… especially oral health to see people sit in the dental chair who've never sat in one before and have some work done is really quite moving. When we had the first one it was really amazing and now we got it [the mobile dental clinic] set up downstairs it's just so great so I think that's massive step forward." (S3)

Support persons noted changes in the club member's health behaviours. They saw that the members were more aware of health issues and able to make their own decisions. They also noticed a few members doing things they wouldn't expect them to do such as drinking water and brushing teeth. Support workers and the volunteer also noticed changes in their own health behaviours with one support worker quitting smoking and the volunteer stating "two weeks ago they had something about the doctor and … I didn't know what to say to the doctor but now I do." (V1)

One support worker (S3) and one presenter wanted to share and expand the program with different agencies and audiences.

> "I would love to see that [the program going to other agencies] … because I think it's needed. And you realise how much is needed when you do some training with other agencies and how lucky we've been to have that opportunity to work with [name of organisation]." (S3)

"I think it's got so much potential ... additional things that could be done." (Pr2)

Participants were asked what they disliked about the Healthy Living program and any suggestions or improvements they had for the program. Club members had no dislikes regarding the program; "I don't have any dislikes. I like it because it encourages you to learn healthy eating, to exercise and just to get out and drink water." (P6). However support workers and presenters described some difficulties with running the program.

> "It can be quite challenging finding presenters that are suitable for that group … it's fairly hard doing adult education with a large group full stop … but then you add in the complexities around low literacy, hearing and sight impairments, people's ability to communicate and understand and it becomes quite a difficult environment sometimes, a challenging environment." (Pr2)

Ideas support workers and presenters provided to improve the program included suggestions for content delivery such as specific session topics, different aspects of health and reinforcing learnt topics from the previous sessions.

> "I do like the smaller sessions. I like the talking to whole group but I think ... like a smaller talk to the whole group and then getting people to come away downstairs … I hear a lot more people talking about it, like the ones that are involved in those small chats. They seem to talk to us about it a bit more. Like they've actually learnt a bit more maybe." (S2)

Continuing brainstorming ideas with the club members to find out what they would like to learn in the Healthy Living sessions was considered important to the ongoing success of the program.

> "There was a lot of suggestions and I think that if we do that [brainstorm] regularly that would keep the program going and getting new ideas, or if they wanna go over … another topic." (S3)

"The more the merrier" (S1)

All club members, except one, thought it was a good idea that the support workers are more involved in the Healthy Living program. The presenters believed more support worker involvement in the planning of sessions to be a good idea if they had time. They believed the support workers

already had quite a lot going on with their current involvement with the social club but would still welcomed more contribution:

> "There's staff [support workers] on the day that are usually really busy, like I'm relying on them to actually run the event, to manage the transport, they're serving food, when clients are getting distressed or need follow up, they're the people providing the client follow up so they're already very involved ... if they wanted a greater role in (pause) I don't know, how the program runs like the long term direction I'd certainly welcome them." (Pr2)

> "I'm often quite aware that the … care workers have a whole heap of expertise that I don't have because they're, they're working and supporting people on a day to day basis in places where they live ... so I think we could definitely consult with them more about how topics are delivered because sometimes they have quite practical advice like oh that'll never work they can't even choose their own GP anyway … which therefore defeats the entire purpose of a topic we might have just spoken about." (Pr2)

Support workers felt they were involved in the Healthy Living program, with some tentative when asked about an increased involvement and doubted whether their contribution would add much.

> "I mean we're not health professionals ourselves …. (short pause) we could possibly guide as to what ... other topics we could follow through with ... that we might think are valuable towards the guys that we support ... through any issues or anything that have come up in the past." (S1)

"The end product's better with participant involvement" (Pr2)

When club members were asked about their thoughts on being more involved in the development and delivery of the Healthy Living sessions, most were happy to provide feedback and felt they had ideas for topics and developing a session:

> "I mean I have ideas basically … it's all just about encouraging" (P2)

> "Proper exercise, dietary you know ... eat the right foods, wear summer clothes, put on some sunscreen" (P5)

Although most of the club members were willing to contribute their ideas towards planning a session, some thought they were already quite involved through their participation in answering questions during the sessions, "I've answered lots of questions at Healthy Living" (P2). Majority of members preferred to plan a session amongst a group rather than by themselves, "Oh I can contribute if I had some help but I just wouldn't do it on my own" (P6). P6 explained why she/he preferred to work as a group:

> "The only reason I don't feel comfort- comfortable running a session is 'cause ... what my opinions are may not be somebody else's, yeah but like not all of other people from different experiences." (P6)

The support persons and presenters were asked about their thoughts around club member involvement with the development and delivery of the program and all agreed that club member involvement is a favourable idea:

> "That's fantastic I think the more people that can contribute the better the programs will be and more diverse information that they'll have access to." (Pr1)

> "It's important that they [club members] are involved and if anybody is willing like if [name of club member] is willing to … have a say or any of the others that'd be great to have their inputs so we're all working together, that'd be really good." (S3)

> "… and it's more important for participants [club members] to hear answers from their peers than it is to hear it from me or a healthcare worker 'cause then you've got the role modelling that goes along with it as well." (Pr2)

Support persons and presenters mentioned various difficulties associated with organising a Healthy Living session together with club members including finding a time and place outside regular club meeting times to plan the session, and deciding how many and which club members to involve.

> "I think that might be difficult to do ... I don't, the only person I can think of would be [name of club member]. I don't know whether the other people will have that capability and I don't think they, I mean I don't wanna say, I don't want that to be a barrier, it'd be good but ... I think it might be proven quite difficult to actually achieve that but I think it's a worth a try." (S3)

Discussion

The Healthy Living program is one of a small number of health promotion programs available to encourage a healthy, physical, social and mental lifestyle for people with intellectual disability. Providing these short, tailored sessions for people with intellectual disability at established weekly social club meetings overcame some of the common barriers to accessing health promotion programs, such as family support, transport, inaccessible environments and financial hardships.[7] All stakeholders, consisting of people with intellectual disability, presenters and support persons, were generally content with the Healthy Living program. The oral health and dental hygiene session was

reported to be the most successful with attitudes to dentists and dental health improving following the session. This is an important finding as oral health and dental hygiene is one area of health that is often poorer among people with intellectual disability in comparison to the general population.[3] Many support persons reported changes in their own health behaviours including learning what to do when seeing a doctor and quitting smoking.

All stakeholders appreciated the organisers efforts to obtain their feedback on the program. Continuing brainstorming ideas with the club members to find out what they would like to learn in the Healthy Living sessions was considered important to the ongoing success of the program. Suggested modifications, such as smaller groups or being able to break up the large group into smaller groups for particular activities, may result in even greater program success. Challenges highlighted in this study included the presenter's skills and experience with working with people with intellectual disability, and their perceived skills and abilities of individuals with intellectual disability. With more training and support, presenters may feel more involved in the program and more comfortable communicating with this audience. With some guidance, people with intellectual disability could also be assisted to develop and deliver a session directed to presenters and healthcare workers, to describe their lived experience. With the help of a project facilitator, seven people with intellectual disability in Northern Island after training designed and presented a value based training program for support staff.[17] Such a session could be included as part of a training package for presenters and support workers involved in the Healthy Living Program.

In terms of support worker involvement in Healthy Living, both people with intellectual disability and presenters welcomed their greater involvement. Support workers were considered to be knowledgeable of the unique needs of people with intellectual disability in terms of their health and their individual capabilities. As the support workers current role within Health Living is quite demanding, involving the running the social club and supporting the members, for them to be

involved in the Healthy living sessions or their planning during club meetings would be difficult. However, people with intellectual disability and presenters all supported their involvement in the presentations. With additional funding and support, a staff-led exercise and health education program modelled on the Health Matters Train the Trainer Program[18] could be developed for support staff to improve the health outcomes for people with intellectual disability in community settings as it has done in the US.

Although feedback is sought from people with intellectual disability, they are not involved outside of their time at the social club; hence they have limited input into the development of the program. On exploring the potential for their greater involvement in the production of the program, we found most Healthy Living attendees were keen to have greater input in developing a session. Presenters and support persons supported the idea of people with intellectual disability being more involved however the practicalities of doing so may present some challenges which echo those found in Chenoweth & Clements' survey of 248 services for people with disability regarding the opportunities people with disability have in participating in the planning and delivery of services.[19] Although people with intellectual disability lacked confidence in their ability to do so, with support, they could become co-presenters to their peers in the Healthy Living Program. In Australia, people with intellectual disability have successfully co-facilitated a respectful relationships education program for their peers.[20]

The major strength of this study is its inclusion of all stakeholder groups. Prosser & Bromley[21] discussed the importance of getting subjective information from people with intellectual disability themselves; however talking to and gaining opinions from individuals with an intellectual disability can also be challenging. Difficulties with interviewing this group include getting biased responses and the tendency for them to acquiesce particularly to closed-ended questions that required a “yes” or “no” response. When a closed answered question was asked, this was done so in an attempt to lead

into further discussion and the answer was treated with scepticism. There were only two presenters, one of whom was one of the organisers of the program and consequently may have had biased responses, but these contributions have been identified.

Conclusions

People with intellectual disability, as well as their support persons, reported positive health benefits as a result of participating in the Healthy Living program, a health promotion program designed for members of a social club, who have intellectual disability. The majority of stakeholders were happy and willing to contribute further to the development of the program. Up-skilling presenters who may be experts in their field but not familiar with adults with intellectual disability may ultimately lead to greater improvements in health outcomes. Providing encouragement and opportunities for support workers to provide input into the sessions could also result more appropriate and well-focussed sessions. Enabling people with intellectual disability, who are the experts on their individual disability, to contribute to the development of the health promoting sessions will ensure the sessions are focused on what is useful to them. The development and evaluation of resources to increase the confidence and willingness of people with intellectual disability and their supporters to contribute would result in more inclusiveness and true coproduction of this and other programs designed for people with intellectual disability.

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Appendix

Semi-Structured Interview Schedule (For People with Intellectual Disability)

Tell me about you

To start, I'll ask you a few questions about yourself.

- How old are you?
- Where do you live?
- How long have you been coming to [Social Club]?

Tell me about [Social Club] and Healthy Living

Now, I'd like to talk to you about Healthy Living at [Social Club].

(Prompt: If participants unsure about 'big picture' questions → ask what happened today in Healthy Living session)

- Please tell me in your own words, what is the Healthy Living program at [Social Club]?
- ***Do you like "Healthy Living" sessions?

  What do/don't you like about them?
- What's been your favourite one?

  (I've heard you've done dental health – did you like that? Can you think of other sessions? Can you tell me about them?)

***Tell me about giving advice/"feedback"**

We will now talk about giving advice and feedback about Healthy Living.

(Prompt: If participant can't think of a time they gave advice → ask about their lives for example choosing an excursion)

- Do you like answering questions at Healthy Living?

  What do/don't you like?

- Do you like the feedback sessions?

  (Remember when [Program Organisers] asked_____. What did/didn't you like?)

- ***Do [Program Organiser 1] and [Program Organiser 2]ask you what you want about Healthy Living? Can you tell me about a time they asked? Do you want them to ask? What would you say?

- ***Do you feel like you could plan a session?

- Do you think it'll be a good thing for club members to plan a session? How do you feel about this?

  Would you prefer to work one on one or in a group when planning a session?

- Do you think it'll be good if [Support Organisation]staff are involved in the planning and development of the Healthy Living programs?

- Does anyone at home ask about what you do at Healthy Living?

  What happens when you talk about Healthy Living at home?

- Do you think you've made changes from the Healthy Living programs?

- Do you have anything else to add?

Semi-Structured Interview Schedule (ForSupport Persons and Presenters)

Can you please tell me in your own words, what the Healthy Living program at [Social Club] is?

Please describe your current role, and if and when you have been involved with the Healthy Living program at [Social Club].

How do you feel about Healthy Living program?

- Likes/Dislikes
- Sense of ownership/connection?

Have you been invited to, or have you participated in any previous feedback sessions or surveys?

- Yes/No
- Why/Why not?
- How did/would you feel about providing feedback?

Should [Support Organisation] staff be more involved in development and delivery of the Healthy Living program at [Social Club]?

How could staff be involved in the development and delivery of Healthy Living sessions?

- Positive/Negative
- Why/Why not?

How do you feel about increased participant involvement in the development and delivery of Healthy Living sessions?

Positive/Negative

Why/why not?

What about the participants planning this outside of the time they are at [Social Club]?

What ideas/suggestions/comments for improving the Healthy Living program?

Yes/No

Specifics

How has Healthy Living at [Social Club] impacted on your daily work?

- If the participants and staff were more involved in the planning and delivery of Healthy Living program, how do you feel your daily work would be impacted?

  Positive/Negative

Can you think of any changes participants have made as a result of Healthy Living at [Social Club]? Examples?

Have you yourself made any changes or learnt something new from the Healthy Living program? Examples?

Do you enjoy sharing your experiences and opinions with others?

Yes/No

Why/Why not?

Do you have anything else to add?

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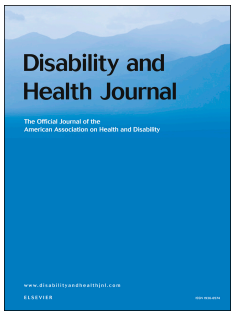

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