

People with learning disabilities, carers and care workers awareness of health risks and implications for primary care

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Background. People with learning disabilities have become increasingly exposed to health risk with the move to community living. Yet, health promotion is poorly developed with a heavy reliance on primary care.

Objectives. To elicit the perceptions of people with learning disabilities, carers and care workers regarding risk factors associated with cardiac disease.

Methods. A qualitative approach was adopted incorporating semi-structured interviews based on vignettes. Twenty people with mild learning disabilities, 10 carers and 10 care workers were recruited. Data were analysed using Miles and Huberman's five-fold process.

Results. In total, 29 women and 11 men were interviewed. A range of health risks was identified with different patterns across groups. There were common concerns around diet. Approximately 50% of participants also had worries regarding 'excessive computer usage', often related to physical inactivity, and a similar proportion identified social isolation as a risk. The importance of safeguarding personal autonomy was stressed in all three groups.

Conclusion. We demonstrated the feasibility of engaging with people with mild learning disabilities regarding health improvement. Participants recognized not only risks but also the subtle interplay of different factors, reflecting a grasp of the complexity of health promotion. Approaches within primary care to health improvement need to acknowledge this level of awareness.

Keywords. Awareness of health, cardiac disease, carers, learning disabilities.

Introduction

People with learning disabilities comprise approximately 2% of the UK population and numbers are increasing due to changing demographics.¹ The policy of institutional closure has led to people with learning disabilities living within the community, with responsibility for their own health. This has resulted in the health care of people with learning disabilities being devolved to primary care.² GPs are often a main point of contact. The average UK practice will have about seven people with severe and 30 with mild learning disabilities on their lists.³ People with learning disabilities have increased health needs compared with the general population but their health needs are often

unrecognized and unmet.¹ Community living has increased health risks associated with lifestyle choices—such as poor diet and smoking—particularly for those living with least support.⁴ It is known that people with learning disabilities are less likely than other primary care service users to be offered preventative health screenings.⁵ Health promotion for those with learning disabilities is poorly developed.⁶

Overall significant inequalities have been uncovered regarding the practice and outcome of health care for people with learning disabilities.^{2,7} A plethora of policy documents have sought to address problems including Learning Disability Service reviews both in Scotland⁸ and England.⁹ The latter have led to the requirement for all general practices to have a register

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of patients with learning disabilities. In England, patients with learning disabilities should also have a health action plan constructed with the help of a health action facilitator. Other solutions for addressing barriers faced by people with learning disabilities in accessing care have included educational initiatives targeting primary care professionals^{7,10} and health checks.^{7,11} These initiatives are geared towards changing the attitudes and behaviour of professionals. Yet, because of the increasing emphasis on quality of life and lifestyle, rather than solely absence of illness, Espie and Brown¹² advocate that health improvement involves a shared responsibility between service user and professional.

Knowledge of health risk factors, and determinants of healthy lifestyles, is advocated for underpinning health improvement programmes.¹³ Professional perceptions of lifestyle-related health risk factors for people with learning disabilities are beginning to emerge.¹³ However, self-report of health issues by people with learning disabilities is lacking. We know very little about people's own perceptions of their needs.¹⁴

The research described here was part of a larger study focussing on the involvement of people with learning disabilities and carers in developing research questions for investigating health risks regarding cardiac disease.¹⁵ Coronary heart disease is the second most common cause of death among people with learning disabilities and rates are increasing due to increased longevity and lifestyle changes associated with community living.¹⁶ Poor cardiovascular fitness of people with learning disabilities has been proposed as one of the main contributing factors for shortening their lifespan and increasing mortality rates.¹⁷ Also, almost half of all people with Down's syndrome are affected by congenital heart problems.¹⁶ In an institutional population, cardiac disease was found in 10% of residents, and management of medical conditions by the hospital staff was generally found to be poor.¹⁸ In a study of 40 general practices in Wales, health checks on 190 people with learning disabilities uncovered 10 cases of previously unidentified cardiovascular disease, four of which were deemed serious.¹¹ These studies underscore the importance of a more proactive approach to managing the health of this population group. In the work reported, we sought to determine views of people with learning disabilities, carers and care workers, on lifestyle-related health risks for cardiac disease. This was in order to address a notable gap in the literature, support self-determination through establishing service users' perceptions of risks and inform and facilitate a shared approach to health care decision making.

Study aims

The key aims of the study were to (i) establish awareness, by people with learning disabilities, carers and

care workers, of health risks; (ii) determine whether different health risks were considered more or less harmful and (iii) identify participants' strategies for risk reduction.

Research design

This community-based study was undertaken in north-east Scotland. Participants included adults aged 16 or over with mild learning disabilities, carers and care workers. A qualitative approach was adopted both because of the lack of previous research to generate hypotheses and our commitment to 'study the interplay of multiple views and voices'.¹⁹ This is reflected in the design and procedures used, such as face to face interviews and focus groups.

Recruitment

This community-based study encompassed Aberdeen and Aberdeenshire covering both urban and rural locations. We chose not to recruit through general practices because we wished to capture lay perspectives of health risks associated with everyday community living. In Scotland, health screening is not routinely offered to people with learning disabilities and we had no knowledge of the health advice offered to any of our participants. We wanted to recruit individuals from a variety of living arrangements and experiences, reflecting different life circumstances. We sought to include 40 participants in this pilot study. This number provided for an adequate breadth of data and reflected the qualitative nature of the research. Half of all participants were to be people with learning disabilities to underscore the importance placed on service users' views.

Contact with potential service user participants was made through community service providers, such as local authority social work day centres and residential supported living accommodation. The community providers were asked to indicate those likely to be interested in taking part in a study and those likely to be able to give informed consent. Candidates were approached by AY as soon as interest was indicated. Twenty adults with mild learning disabilities were recruited as described. Also 10 carers and 10 care workers participated because of (i) their key roles in supporting people with learning disabilities and (ii) the need for health improvement strategies to be acceptable to both service users and key supporters. Carers were defined as those who 'look after family, partners or friends in need of help because they are ill, frail or have a disability'. The care they provide is 'unpaid'.²⁰ Ten carers and 10 care workers were recruited through local authority social work departments, Voluntary Services Aberdeen Carers Centre and other voluntary organizations. Service users, carers and care workers were not matched in that they were not selected

because they formed part of the same household. Only people able to give informed consent and familiar with the English language were included. Those with a significant visual impairment were excluded because pictures were used in the interviews.

Consent

The research protocol included a detailed plan for obtaining informed consent from people with learning disabilities.¹⁵ One of the authors (AY), who undertook all the interviewing, met with each service user and an independent witness to explain the project, provide information on the study, answer questions and seek written consent. Arrangements were made to return on another occasion, at least 48 hours later, to conduct the interview and consent was confirmed prior to this. Telephone contact was made with carers and care workers to explain the project and seek verbal consent. Written information was sent prior to the interview and written consent was obtained before commencement.

Interviews

Interviews of approximately 45 minutes duration were held between February and October 2004 and, given consent, were audiotaped. All interviews were undertaken by the same person (AY) to maintain consistency. All interviews followed the same format, and the same procedures were used with all 40 participants. Vignettes, reflecting the recommendations of Farmer *et al.*,²¹ were developed to:

- provide a simple, non-threatening means of engaging participants;
- provide stimuli for discussion on specific topics;
- enable participant discussion of health issues in a 'safe' context whereby comments could be made within the framework of a story and
- provide participants with choice around whether or not they wished to disclose personal information regarding managing health risks.

The 'lifestyle' vignette (Box 1) describes key behaviour which might lead to future risk of heart disease, encompassing physical inactivity, obesity as a result of eating habits and cigarette smoking.

To facilitate discussion of the vignette, pictures (symbols and photographs) were used. Also, a modified version of Talking Mats—a communication framework to help people express views and feelings—was adopted.²² The mat helped focus participants' attention by providing a defined background on which a vignette was presented using a large font. The researcher read aloud the vignette while placing pictures alongside to reinforce understanding. The interviewer posed questions regarding the participant's understanding of health, knowledge of health risks,

Box 1: *Cardiac disease vignette used at interview*

John is a young man with learning disabilities. He lives in a flat with one other man. His care worker sees him at home two times a week. John's main interest is playing computer games. He gets up at lunchtime and plays on the computer every afternoon and most evenings till late. He wants to get to level 3 on his new game. Later, he gets hungry so he has five or six packets of crisps and a large bottle of coca cola. He now weighs 15 stone. John usually smokes 10 cigarettes a day while on his computer. The only walk he takes is to the pub at the end of the road for a pint of beer on Saturdays.

strategies for risk reduction and identification of health topics for future research.

We wanted to avoid questioning participants directly about their own health and health experiences lest it was regarded as 'a test'. We wished to avoid causing distress by opening up any perception that people could be blamed for their own health problems. The vignette-based approach was considered non-threatening and minimally intrusive in that disclosure of personal information was determined by respondents.

Considerable efforts were made to make interviewees as comfortable and relaxed as possible by conducting interviews in a venue chosen by them, having a supporter present if desired and pacing the discussion according to tolerance levels. All interviews were transcribed verbatim.

Data analysis

Qualitative analysis followed the five-stage process recommended by Miles and Huberman²³ namely: (i) familiarization; (ii) identifying a thematic framework; (iii) indexing; (iv) charting and (v) mapping and interpretation. Data analysis was completed by AY and AW, both of whom had experience of working with people with learning disabilities.

Both AY and AW read all the transcripts independently and identified main themes and categories. A coding frame was developed to reflect the study objectives, key risk factors in the vignette and issues identified by participants. Although three separate coding frames were used, there was a commonality of codes to reflect similar responses across service users, carers and care workers. Themes and codes were refined and validated by all three authors. The sub-headings employed in the following section reflect the main themes identified from the analysis.

Findings

Twenty-one service users (one of whom withdrew at a later stage), 10 carers and 10 care workers gave written consent to participate in interviews. Two service users refused permission for audiotaping of the

interview, although they were happy to proceed on the understanding that AY would make short notes. These two interviews were written up more fully by AY within 24 hours. In the quotations, the first letter of the identifier denotes group i.e. S, service user; C, carer and W, care worker.

Characteristics of participants

Service users. Twelve women and eight men were interviewed. Participants' age ranged from 18 to 68 years (mean 41 years).

Half resided with family members and the majority of the remainder lived in a variety of supported living arrangements. Two men lived independently (Table 1).

Carers. The majority of carers were women (9:2) with one married couple participating in a joint interview. The age range was 31 to 67 years (mean 57 years). All carers had been providing support for a considerable number of years ranging from 14 to 37 years (mean 28 years).

Care workers. The majority of the staff were women (8:2), their ages range from 24 to 59 years (mean 45 years) and most had considerable experience of working in the caring sector (range from two and a half to 40 years, mean 16 years). All worked full time (mean 36 hours). Three interviewees reported direct experience of being a carer in past years.

Interview participation

All interviews were completed and the vignette prompted lively discussion. All service users were engaged and were able to forward views, although in

some cases use of language and levels of understanding appeared limited. The behaviour portrayed within the vignette of John was recognized by participants, and some carers and care workers spontaneously commented that these patterns of behaviour were common among many people with learning disabilities.

Knowledge of harmful effects of behaviour

A range of health risks was identified, although differences emerged regarding how frequently they were referred to by the three groups (Table 2). There were common concerns around diet. Approximately half of all participants in each group had worries regarding excessive computer use, and these often related to risks associated with physical inactivity. Also, social isolation was identified as a health risk by over half the carers and care workers. Although service users did not specify isolation as a risk, five spontaneously described health benefits associated with social contact and interaction.

Participants from all three groups identified specific harmful consequences from behaviour. For example, there was widespread appreciation of harmful effects of poor diet and its association with disease, especially relating to obesity. Service users commented: If he's having six packets of crisps ... it's all the fat. Yes and the sugar. Because coca cola will have sugar which is quite bad. [SB] It puts on too much weight. [SM] Too much sugar I suppose ... damages your health, heart. [SF] A carer said: He's eating and drinking the wrong kind of stuff ... not getting any nutrition [CN] and a care worker: I don't think it (the diet) would be good for his heart. [WG]

TABLE 1 *Profile of service users*

Age	Sex	Home circumstances	Home support
23	F	Lives with mother and her partner	User unsure
50	F	Lives with parents (hoping to move out soon)	Only from family
41	M	Lives alone, copes independently	Parents help if needed
18	F	Lives with mother and brother, respite 1 week every 2 months	Care staff morning and evening Monday to Friday
38	M	Lives alone, Monday to Friday and visits family Saturday to Sunday	Support worker Monday to Friday
68	F	Lives in residential care home for elderly, has own room	Staff available over 24 hours
53	M	Lives with one other man in supported accommodation	Daytime staff, no overnight support
47	F	Lives with sister and other family (six people)	Only from family
46	F	Lives in supported accommodation with eight others	Staff available over 24 hours
44	M	Lives alone, has lifeline to summon help in emergency	Care worker once per week
47	M	Lives alone independently	No support
58	M	Lives with mother	Only from mother
47	F	Lives with mother and brother	Only from family
39	M	Lives with mother	Monthly input from care manager
47	F	Lives with parents, helps to support parents	No personal staff. Nurse supports parents
21	F	Lives with parents and two brothers	Only from family
23	F	Lives in supported accommodation with two others	Staff available over 24 hours and family input
37	F	Lives alone	Staff support, a.m. and p.m.
47	F	Lives with mother	Infrequent input from care manager
68	M	Lives alone in housing for elderly	Staff support a.m. and p.m.

TABLE 2 *Main health risks identified by participants*

Risk factor	Service users, <i>n</i> = 20	Carers, <i>n</i> = 10	Care workers, <i>n</i> = 10
Poor diet	15	7	7
Smoking	17	3	6
Excessive use of alcohol	15	–	–
Excessive use of computer	10	6	4
Social isolation	–	7	6
Inappropriate sleep pattern	6	5	5
Physical inactivity	6	4	2
Lack of mental stimulation	2	2	1

The relationship between computer use, inactive behaviour and weight gain was well recognized: Depends on how long he plays on the computer ... he'll get fat as well. [SM] Just sitting all the time ... that's the reason for the weight going on isn't it? [CK]

Social isolation was viewed as especially harmful to mental health as illustrated below:

I think mentally it would affect you, being on your own. It affects my own mum and my brother, how they can cope with people from the outside world. They have lost that skill and I think that is detrimental in anybody's health. [CP]

He's self isolating He would never tell anybody and things would progress to a level of physical illness People may not ever feel comfortable enough to discuss any major health concerns, or personal concerns and things go missed. [WH]

Not a very interesting life is it? He should be doing more ... he must get bored sitting in all day. [SJ]

I don't think it is particularly good either from, I suppose, more of a mental health situation. But it can affect you physically, as well, of course if you are on your own and you get depressed. [WD]

Differences in perceptions of health risks across the groups were found regarding alcohol consumption. Three quarters of service users had concerns about excessive alcohol consumption, whereas carers and care workers viewed occasional drinking as acceptable.

Service users had a number of concerns regarding alcohol-related behaviour and these included the following: (i) transient health discomfort such as headaches/vomiting; (ii) liver damage; (iii) risk of alcoholism and (iv) risk of accidental injury, for example road traffic accidents. Conversely carers and care workers felt that provided drinking was limited (around a pint of beer a day maximum), it could be beneficial in promoting social contact.

Although health risks from smoking were identified by people in all groups, carers commented on smoking

less frequently than care workers or people with learning disabilities. Dangers identified were damage from passive smoking, serious disease/death, nicotine addiction and injury from fire. However, benefits were identified also as reflected in the following quotation from a carer:

He maybe thinks of that (smoking) as something that (means) he's grown up. If he's having a cigarette and joining in with other people ... He (maybe) thinks that (he will be) ostracised for not smoking. I don't think he should smoke ... but I also don't know how he regards his smoking. If you used it to smoke socially, as a thing to build up his confidence, then maybe for him it's not too bad. But as a particular health thing then cigarette smoking isn't good. [CS]

Risk reduction

Knowledge of health risks alone was viewed as unlikely to affect behaviour as reflected in the following dialogue with a service user:

SL: I think he would know that smoking would give him heart attack and also cancer. He knows that.

AY: Why do you think he still does it?

SL: Habit.

Behavioural change management aimed at-risk reduction was seen as a highly complex process. Service users pointed to both consequences and challenges regarding changing behaviour:

Well it is not easy to change or to think of what's good or what's not healthy ... yes it's a bit hard maybe. [SI] Smoking is bad for you Well some of them get ill natured when they stop It's the same when they're drinking, they get ill natured when they cannae get it ... it would be hard to do. [SG]

Participants' main strategies for risk reduction included:

- changes in consumption patterns, for example switching to diet coke or increased intake of healthy food such as salads;
- increased activity, for example walking, swimming or going to the gym and
- nicotine substitutes, for example chewing substitute gum, using nicotine patches or sucking polo mints.

Some participants suggested that in order to achieve harm reduction, a range of major changes would be needed in how people led their lives. A service user

highlighted the importance of a positive attitude towards life and ensuring social interaction as follows:

SN: His attitude ... Go out on the town on his own or with his carer ... Get more friends for him, boyfriends or girlfriends.

AY: So you think having friends is good for keeping healthy?

SN: Yeah

In addition to identifying strategies for reducing health risks, participants from each of the groups raised the importance of safeguarding personal autonomy.

The individual's right to choose

Enabling individuals to have a choice was regarded as highly desirable across all participant groups. A service user described the complexity of balancing choice with healthy behaviour as follows:

Not maybe tell him but advise him ... because really he doesn't want to change his way of life ... It's up to the individual at the end of the day ... I would turn to (his care-worker) and say, well I will do what I like, you know that sort of thing, it's my life I will do what I want to do. [SK]

A carer highlighted that people with learning disabilities have the same rights to choose as the general population:

I would hate that anybody was forced to do something that they didn't want to do ... It is alright for other people to still smoke 40 a day and all that stuff, or alcoholics and all that sort of things. We have the right, so, no I don't want to take help, so why should they? [CP]

The challenges of impacting on strongly held beliefs were described by care workers:

Everybody has a choice, and if he doesn't want to change his lifestyle, then it doesn't matter if I put dynamite under that person, they are not going to change ... I mean smoking, again that's his decision, I would advise him to cut down. [WH]

You can't do anything unless you engage him. You really need to find out what he wants. What does he see as important in his life? ... I think that the skill of being a care-worker for someone like John is to engage John and help him to make informed choices that are going to improve his lifestyle, although he, at first, doesn't recognise that. [WG]

Many participants highlighted how risk reduction and personal choice were not easily reconciled.

Risks and complexity

Participants in each group highlighted that harm was more likely to arise through a complex interaction of risk factors, rather than through a single cause. Despite contrary evidence in this study, participants held a widespread belief that people with learning disabilities have difficulty understanding health risks as illustrated below:

Computer—his care worker could help him ... He won't understand ... Yes because it says that John is a young man with learning difficulties, he might not understand. [SB]

Understanding that his lifestyle at the moment isn't very good for him ... He won't understand unless it's explored with him ... I would think that John would not see five or six bags of crisps and a large bottle of coke as the reason why he's overweight. [WG]

Other risk factors identified included amount of exposure to risks and inadequate professional support as illustrated below:

Coke has got a hell of a lot of sugar in it, and there's obviously a lot of caffeine in coke as well, which is why he's sitting up all hours of the night because he's stimulated by the caffeine. He's sitting gaming half the night therefore he can't get up in the morning. [WG]

The people who are organising his care feel that they shouldn't be imposing too much. But obviously that hasn't worked out because he shouldn't have got into this routine. [CM]

Professional support

The need for professional support for achieving healthy living was emphasized by participants from all groups. Service users recommended seeking a variety of input from care workers, counsellors, psychologists and dietitians. Care workers raised multiple issues, including perceptions of their own responsibility for the health of people with learning disabilities, as illustrated below:

People have a choice, and it's really quite difficult to allow someone to have a pudding everyday, instead of an apple and a yoghurt. But they have the choice. But on the other hand when you see them increasing in weight, unable to go for a walk, unable to get exercise because of their increased weight, and there may be mobility problems—and you think of the stages further on in life—like heart problems—it's a big concern. [WC]

Care workers also pointed to the complexity of supporting service users to manage risks:

You are nae exactly like going to force him to do anything. You are maybe just gan (going) to hint a wee bitty ... like “do you nae fancy doing this” just so that he disnae feel he is being pushed into anything. Cos if he feels he is gan to be pushed into it, he is nae exactly (going to) want to, cos he wants his independence. [WB]

It doesn't seem to register that people [have] dental requirements ... They've got very bad breath and decay and a lot of them are very scared of the dentist. So a lot of carers (think) it's so much hassle to go through that (to the dentist) that a lot of decay happens. So I think a lot more needs to be done to do with that. [WI].

Some carers viewed the support of care workers as crucial:

Somebody else has to step in to help them—the care-worker. If they can't understand the person that they're looking after you cannae start. [CK]

The care-worker worries me. Presumably she should be his enabler to do things ... enabling and overlooking his wellbeing, so what's she thinking about? My perception of a care-worker is looking after the total wellbeing of the person that they are supposed to be supporting and caring. Not, em, how would I put it, not just muddling along because everybody is happy. [CO]

The far reaching implications of behaviour patterns impacting on health and wellbeing were encapsulated by a carer in the following dialogue:

CK: Some folk would look at that (the vignette) just thinking that there's nothing wrong with that. He's living and that's it. But there's more to life than that, if he's able to do more.

AY: And you think that it's important that people are helped to reach their potential?

CK: Oh aye. Without a doubt. That's the key to life isn't it?

Discussion

This study enabled the voices of people with learning disabilities to be heard, as previously recommended.^{14,24} The range of participants was broad in that the ages of men and women spanned from 18 to 68 years, service users' living circumstances were diverse and carers had long experience of caring in a number of different settings. The investigation provides insights

into awareness of risk factors and their management. Participants not only recognized health risk but also the subtle interplay of factors. For example, physical or practical aspects of everyday living were described in the vignette, yet social circumstances were highlighted as potentially leading to emotional distress and mental illness. This research clearly demonstrates participants' ability to grasp the complexity of health risks. It may well be that our findings regarding people with learning disabilities are transferable to the general population and thus need to be taken into account in primary care public health strategies. The needs of people with learning disabilities reflect problems already known to exist in the general population, but because of the nature of learning disabilities and associated comorbidities, they have higher unmet needs.

Despite having increased needs, people with learning disabilities often receive a poorer primary care service compared with the general population due to difficulties with communication, advocacy and access.²⁵ Strengthening the interface between the primary care team and people with learning disabilities, carers and care workers is crucial in addressing inequalities. Innovative initiatives for engaging service users/carers in partnership within primary care are beginning to emerge including increasing consultation.²⁶ Yet, there is some evidence that relationships can be problematic between professionals and clients.²⁷ The perspective of some health professionals which requires 'patient compliance' in changing health-risk behaviour has been seen as unhelpful.²⁸ The recent public health guidance from the National Institute for Health and Clinical Excellence (NICE) regarding reducing smoking and physical inactivity, in fact, recommends that primary care professionals 'advise' patients regarding specific lifestyle choices.²⁹ The NICE guidance itself has been criticized for overemphasizing the individual's personal responsibility for their health and underemphasizing social influences, such as the role of food producers, which have impact.

People in all three participant groups strongly supported the right of individuals to make personal choices regarding everyday living, even where this increased health risks. Our study points to the importance of framing health-related lifestyle choices in ways which take into account the complex realities of everyday living, the individual's social circumstances, together with the desired long-term health outcomes. This is a particular consideration for those, such as people with learning disabilities, whose lifestyle is disadvantaged or restricted and who may gain emotional comfort or pleasure from unhealthy activities. For example, eating heavily promoted but unhealthy food or gaining peer acceptance through smoking.

People with learning disabilities living with least support have been seen as harder to engage in health consultations, including within primary care.^{4,26} The

emphasis in the interviews on individual's right to choose is of particular interest given the impact that choice has been seen to have on the National Health Service—provoking intense debate.^{30,31} Our work indicates that considerable challenges exist regarding responsibility for risk and providing support. While participants identified the need for support in changing behaviour, 'somebody else has to step in to help them' [CK], they also strongly championed personal autonomy, 'it's my life, I will do what I want to do' [SK].

Thus, people with learning disabilities are likely to have complex support needs. Carers and care workers have been regarded as important facilitators of health consultations for many service users.^{26,32} For those with more severe learning disabilities and major communication problems considerable challenges remain.³³ In such circumstances advocacy may prove impossible and supporters may need to assume more of a protective role for those in their care. Recognition of whose needs are being represented then becomes important.

In our study, care workers were viewed as key supporters. They were seen to need an in-depth knowledge of clients, as well as considerable skills, so as to inform, guide, negotiate and facilitate risk management. This they were required to undertake while avoiding undue influence on the life choices of individuals. Balancing proactive care with having respect for client autonomy necessitates care workers having highly developed skills within the context of clear practice guidelines. This has major implications for workforce education and development. In any event, it will be important for staff in primary care to engage with carers and care workers in helping people with learning disabilities to reduce risks. To date it appears that there have not been particularly close relationships between care workers and the primary care team and these need to be developed. The increasing integration of public health across local authorities and primary care trusts in England is helpful in this respect.

While the qualitative nature of the study is valuable in providing insights, it should be acknowledged that our study is small scale thus the findings cannot be generalized. The research specifically focused on lay perspectives and we have no knowledge of health professionals' advice to participants regarding health risks. Also, participants with an interest in health were most likely to have volunteered for the study, which will have introduced bias, together with the high proportion of women participating. However, qualitative methods are well suited for this study, an area in which there is very little previous research.

Additionally, this study has demonstrated that it is feasible to engage people with learning disabilities and their supporters regarding health improvement. Moreover, it is essential that there is dialogue to establish appropriate approaches to health promotion,

including concerning programme development. It should not be assumed, for example, that pre-existing smoking cessation sessions will be suitable for people with learning disabilities. Targeted approaches are needed, building on the knowledge of primary care team members with a special interest in learning disabilities. Our recommended strategies for supporting the educational and health needs of service users and their supporters include the following.

Engaging with individuals in health improvement

Traditionally, the approach of health practitioners has been paternalistic.³⁴ Our findings point to a more inclusive style of interaction highlighted by participant WG, 'You can't do anything unless you engage him. You really need to find out what he wants. What does he see as important in his life?'

Managing risk through behaviour change

People with learning disabilities need to be empowered, by professionals and supporters, to make health-related choices with which they are comfortable. In particular, an incremental approach is essential, such as a gradually reducing cigarette smoking or increasing time spent walking, as suggested by our participants.

Education and training of supporters

The education and support needs of carers and support staff emerged strongly in this study, echoing the findings of Kerr *et al.*¹⁸ Proactive methods of supporting their learning and development are urgently required.

Conclusion

Our work has started to unravel key elements within risk, and highlights issues, which need to be addressed by those working in primary care. A collaborative approach between practice staff and local authority care workers and people with learning disabilities themselves is most likely to have a positive impact on health.

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Declaration

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