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What are the views of adults with an intellectual disability (AWID), carers and healthcare professionals on a community falls management programme for AWID: a qualitative interview study in the UK

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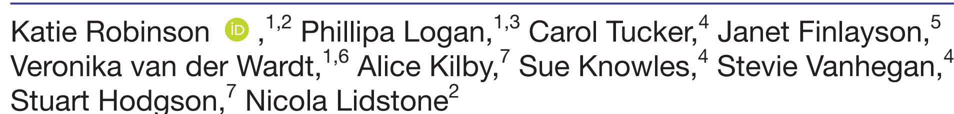

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ABSTRACT

Objectives The aim of this study was to refine a draft of the ACTiON FALLS LD programme based on the views of adults with an intellectual disability (AWID), carers and healthcare professionals (HCPs).

Design, setting and participants The semistructured interview study included HCP as well as AWID and carers supporting AWID living in the community. Community settings included sheltered living, supported living, AWID living at home with family carers or independently. The interview study explored the first draft of the ACTiON FALLS LD programme as well as the wider falls management for AWID. Interviews with AWID were developed to include a range of approaches (eg, case studies, pictures) to support inclusive participation. Individual interviews were digitally recorded and transcribed. Researcher notes were used during interviews with AWID. All data were analysed using the principles of framework analysis.

Results 14 HCP, 8 carers and 13 AWID took part in the interview process. Five key themes were identified: programme components, programme design, programme approach, who would use the programme and programme delivery.

Conclusions The views of AWID, HCP and carers showed the need to consider the impact of risk perception, anxiety and fear of falling in the adaption of the ACTiON FALLS programme. The programme needs to be accessible and support the inclusion of AWID in managing falls and ultimately fulfil the requirement for a proactive and educational tool by all.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Collaborative research including the views of adults with an intellectual disability (AWID).
- ⇒ Research methods designed to support the meaningful inclusion of AWID and carers.
- ⇒ The definition of a carer was deliberately broad; however, this may have limited adaptions to the programme that account for this range of views.
- ⇒ The healthcare professionals participating were primarily physiotherapists and occupational therapists which may not reflect the broad range of professionals involved in falls management.

BACKGROUND

Falls can have a significant impact on the lives of adults with an intellectual disability (AWID)[1 2] and lead to reduced independence, reduced activity and an increased burden on carers. The rate of falls and injuries in AWID is high[3] with significant associated personal and health and social care implications. Falls management research has primarily focused on the general older population often excluding AWID.[4]

Fall prevention strategies that are specific to AWID need to be different to those for the general older adult population[5] as AWID have specific reasons why they might fall such as side effects from medications and alerted gait patterns. There are also differences in the support networks and clinical services working with AWID[6] and tailored strategies to manage falls risks are needed.[7]

The ACTiON FALLS programme is a systematic falls management intervention that was coproduced by clinicians, researchers, public, voluntary and social care organisations and has been shown to be of benefit for older people.[8] This intervention is useful, as it has been developed for a population of older people who are at higher risk of falling. However, this programme has not specifically been developed or evaluated to support

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AWID. The differences in risk factors for falling, patterns of falls, ways of delivering the actions to reduce risks and community settings where people with an intellectual disability are supported, require the development of a revised version of the ACTiON FALLS programme.[3 5 9 10] The prevention and screening of falls risks in AWID are more likely to be supported by services and clinicians with no specialist knowledge of falls. If AWID are supported within specialist falls services, clinicians in these services are often responsible for the care of older people rather than for AWID. It is therefore important that clinicians and carers across services are supported with an appropriate tool designed specifically to meet the needs of AWID rather than being expected to apply a general tool.

A programme of research is underway to adapt the ACTiON FALLS programme for AWID. Based on the Medical Research Council Framework for developing and evaluating complex interventions,[11] the programme of work includes using existing published evidence, the views of stakeholders, a consensus process and a proof-of-concept study to adapt the ACTiON FALLS programme (process outlined in online supplemental file 1).

The existing ACTiON FALLS programme, which supports older people was used to develop the first draft of the programme for AWID. It was tailored for AWID using an existing clinical assessment for AWID and what is known about their falls and falls risks from existing literature.[5] For example, the importance of including the experience of carers was considered as well as specific risk factors such as epilepsy and risk perception. An extract of the draft programme is included in online supplemental file 2. This draft was used to provide the basis for gathering stakeholder views on the content, design and format of the programme. The programme will be referred to from this point as the ACTiON FALLS (learning disability) LD programme as learning disability was chosen based on feedback from lay collaborators at the start of the research programme.

There are two components to the draft ACTiON FALLS LD programme: component 1 was an easy read version asking AWID about previous falls, what is important to them and what worries them about falling. Component 2 is a detailed checklist aimed at carers and healthcare professionals (HCP) listing the factors that may increase the risk of a fall with suggested actions to reduce these risks.

The aim of this qualitative interview study was to guide the development of the ACTiON FALLS LD programme based on the views of AWID, carers of AWID and HCPs working with AWID in the community.

METHODS

Design

The study design and conduct were developed in collaboration with patient and public partners including carers and AWID to meet individual needs and maximise inclusion. The protocol is presented in online supplemental file 3. The following approaches were used:

- Individual face-to-face or virtual semistructured interviews with HCP and carers of AWID.
- Individual face-to-face or virtual semistructured interviews with AWID with a member of their usual care team present.
- A series of face-to-face group interviews with an established community group of AWID. The inclusion of a group interview approach has been chosen to maximise access and generate discussion in a familiar environment.

The individual and group interviews were carried out over multiple sessions to help develop a rapport with participants and allow them to feel able to express their views more freely.

Patient and public involvement

Two patient and public representatives attended the study management meetings as members of the research team and were involved in the research design, interpretation and dissemination of the findings. Strategies to support the inclusion of AWID were identified by a group of AWID, their group leaders and researchers working in this field. These strategies included undertaking the interviews over several visits, the use of an information video to explain the research study and the study being introduced by a person familiar to the potential participant.

On completion of data analysis, the results were discussed with the community group of AWID with the study findings summarised in a video.

Participants and setting

AWID living in a community setting as well as HCP and carers supporting AWID in a community setting were invited to take part. Community settings included sheltered living, supported living, AWID living at home with family carers or independently.

AWID were included if clinical service criteria applied (18 years and over living with an intellectual disability as characterised by significant cognitive impairment, significant impairment in adaptive functioning, with onset before the age of 18). Group members who identified as having an ID were included. This also included groups that supported adults with ID and autism. It is estimated that 32% of people with autism have an ID, with a further 24% having a borderline ID.[12] To ensure an inclusive approach, diagnosis or type of intellectual disability was not required for participation. HCPs were defined as having a professional registration with a relevant professional body and experience of working in a community setting with AWID. HCPs were recruited from across the UK. Family and formal carers were included to capture the breadth of support systems for AWID and were recruited from across one geographical location in the UK. A carer was defined as a relative or friend providing face-to-face support on most days or a paid care staff or support worker working with AWID.

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Recruitment

HCPs were recruited through professional networks and specialist interest groups such as the Chartered Society of Physiotherapy, the Royal College of Occupational Therapists and the Royal College of Nursing. Carers were recruited through community groups, residential facilities and supported living facilities as well as through an National Health Service (NHS) clinical intellectual disability service in one geographical location in the UK. AWID were recruited from an established community group and through an NHS clinical intellectual disability service in one geographical location in the UK. An overview of the recruitment process is outlined in online supplemental file 4.

Ethics

All HCPs and carers gave written informed consent prior to the interview being conducted. With consent, interviews were audiorecorded and transcribed verbatim.

For individual interviews AWID gave written or witnessed informed consent. For group interviews, a process model of consent was used based on stakeholder views and previous research in this area.[13] This approach was designed to maximise inclusion for AWID. Study information for AWID was offered in an easy read participant information sheet, easy read consent form and participant information video (https://www.nottingham.ac.uk/research/groups/communityrehabilitation/projects/falls-management-programme/developing-a-falls-management-programme-for-adults-with-intellectual-disabilities.aspx).

Data collection

The draft ACTiON FALLS LD programme (extract outlined in the introduction and online supplemental file 2) was sent to participants prior to the interview to allow them to consider their views prior to the discussion.

Coauthor NL (female) working as a clinical researcher conducted all individual and group interviews. NL is a registered physiotherapist. Participants were made aware of NL's professional background in introductory meetings to discuss the study.

HCPs and carer interviews were structured to explore the presentation, wording and format of the draft ACTiON FALLS LD programme as well as detail on the risk factors for falling and strategies for supporting AWID to manage falls. Interviews were managed to last no longer than 60 min. With consent, interviews were audiorecorded and transcribed verbatim.

For both individual and group interviews with AWID, the interview schedules were developed to include a range of approaches to support inclusion (online supplemental file 5). Case studies and scenarios were used to support discussion which included written, pictorial and verbal methods as well as AWID discussing their ideas in pairs then as a larger group to allow time to consider their thoughts. Views of AWID were captured during the interview using flipchart and field notes. Summary statements from these notes are presented for AWID rather than direct quote due to the nature of the data collection process.

Analysis commenced during data collection to allow the sample size for all groups (AWID, carers, HCP) to increase until data saturation was reached. For the purpose of this study, data saturation was achieved when no new subthemes could be developed.

Data analysis

Data (from the transcripts, field notes and flipchart summaries) were managed using Microsoft Excel and analysed using the principles of framework analysis.[14] The AWID group members and individual were given the opportunity at each interview session to review their previous questions and answers and give further feedback. The framework method outlined by Gale *et al*[14] was adapted to start with a predefined framework at the first draft of the ACTiON FALLS LD had been developed. The interviews, therefore, explored predefined topics and themes. The steps we undertook are outlined below:

- Predefined framework developed: A predefined framework was developed based on the first draft of the ACTiON FALLS LD programme. This ensured that the framework was logically developed using expert views and the current literature. To allow for any views expressed through the interviews that did not fit with the predefined framework an additional code of 'other' was added to ensure this data was not missed. This framework could be adapted in the context of the data through the creation and removal of codes.
- Transcription and familiarisation of the data: Transcription was undertaken by an external transcription company. The researcher (NL) read and re-read the transcripts, field notes and flipchart summaries to become immersed in the data.
- Applying the analytical framework: Codes within the framework were applied to each transcript using an Excel spreadsheet. New codes were generated by the researcher when reading the transcripts. The completion of this stage was done by one author (NL). Sections of the data were summarised within the framework to allow for efficient management of a large amount of data. The application of the codes was discussed by two researchers (NL and KR).
- Thematic charting: The columns in each code of the framework were summarised to present the key perspectives of each theme. Overlapping themes were combined to summarise the data. This stage was done in discussion with two researchers (KR and NL).
- Interpretation: The researcher kept field notes and reflections throughout the data collection and analysis stage to facilitate emerging interpretation of the data. The study team discussed the summarised data to explore the interpretation. This revised the overall framework and thematic summaries.

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Table 1 Summary of programme approach

Subtheme	Description	Supporting evidence
Standardised	The programme should reflect core standards and promote current best practice and evidence to provide consistent national guidance that could be used to support further understanding and research	'…something that I could use or adapt or just get ideas from because we have nothing. I have nothing standardised here at the minute'(HCP004 -OT) 'To have something that's specific to learning disabilities that covers across the whole of the country and the UK would be really great'(HCP001-PT) 'It would be lovely to have standardised assessment tools because then we could research, we could get a bit more understanding of the population, but everyone uses something very different'(HCP001-PT) '…some sort of, yeah, tool, standards, pathways, anything like that I think will be really welcome and much needed…'(HCP006-PT) '…pulling something together that would give us a more consistent approach.'(HCP008-PT)
Educational and awareness raising	To be educational, enlightening, empowering and encourage action in a proactive and reactive way for clinicians, carers and AWID	'I think there are somethings that maybe we think are quite obvious that providers or families probably don't realise could present a risk. So I think it is quite useful in terms of framing those risks. And then, you can have a conversation about what—because often, people will say well we already do this, or we already do that, so it also brings out some positive things that people are doing already'(HCP008-PT) 'I think having more focus on it does get people thinking about kind of other like environmental factors or health factors of the person or you know other things'(CAR002) '…it's really helpful to have the action because there are certainly things there that maybe a junior physio or physio that doesn't work in falls all the time, then it's important that you're not going to miss things'(HCP001-PT) '…obviously keeping adults with intellectual disabilities safer but also giving them more control and power over their own safety' (CAR006)
Identify falls risks and promote action	Identify individual falls risks, risk perception and initiate actions to reduce these risks	'I ask the carers in between the two weeks that I do the visit is to go through that each time and really gauge their understanding and awareness. I think that's the best way, so then they're more clear on what the falls risks are and why this question is being asked'(HCP002-RN) 'I sometimes feel like people maybe just see falling as a real, just a physical issue, you know, oh they've got older or, I don't know, they've fractured their hip last year, it's seen as a real physical issue, which obviously there are intrinsic physical factors, but I think it's opening the eyes of well actually, no, look at all these things that you can keep on top of, so you can make sure that—we're not saying that if you do all this, this person's never going to fall again, but what we're saying is if we can keep on top of all these things then we're giving that person the best chance of not falling or reducing the risk as much as possible….'(HCP009 -PT)
Support differences in risk perception	Risk perception is subjective and different from real risk as affected by wide range of factors for example, context/cognition	'I think sometimes it's really helpful to go through logically, because I think there are somethings that maybe we think are quite obvious that providers or families probably don't realise could present a risk. So I think it is quite useful in terms of framing those risks. And then, you can have a conversation about what – because often, people will say well we already do this, or we already do that, so it also brings out some positive things that people are doing already'(HCP008 -PT) AWID Group interview: Range of views on falls risk and worry including not worrying about falling, being concerned in new places and forgetting about possible risks that could cause them to fall
Enabler for equality for AWID	Facilitates equity in AWID falls services and in AWID voice and involvement in their care	'Like a pathway so that we know that we're providing sort of an equitable service for someone with a learning disability to someone without a learning disability who has falls'(HCP009-PT) '…all people with a learning disability have the same, should have the same access, the right to access falls clinics'(HCP001-PT) A tool that helps the professionals record what they need but also makes sense to somebody with a learning disability or to their carer [Researcher Field Notes following carer interview) AWID Group Interview: To be consulted as group often felt decisions were made without them

AWID, adults with an intellectual disability.

A summary of the analysis process for theme 1 is presented in online supplemental file 6.

RESULTS

Recruitment and participant characteristics

- Fourteen HCP undertook an individual interview, all with 5 years or more clinical experience (six physiotherapists, five occupational therapists, one speech and language therapist assistant and two nurses). All HCP interviews were conducted remotely over phone or video call.
- Eight carers undertook individual interviews (two parents of AWID, one manager of an AWID charity, one quality audit developer for AWID charity, two care staff working in domiciliary settings, one carer working in an AWID college and one carer for an

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Table 2 Summary of programme delivery

Subtheme	Description	Supporting evidence
Bridge information and transition gap	Programme to provide a marker of current and changing abilities that could be used across transition points	'I think it's really good to have a kind of baseline about where people are now so that when we are kind of going back and making those referrals, we can say actually this is how they have been'(CAR002) 'Particularly for adults with learning disability it becomes so disconnected when they move from children and young people's services into adult services, suddenly if you've got any kind of physical impairment suddenly that's dealt with by somebody who doesn't know that you have epilepsy and you also have a consultant neurologist who's also looking at one aspect of your care, so it becomes very disjointed in adult life'(HCP007-RN)
Completion across settings and service	Flexibility in the programme to allow completion across community settings and services	'People may have falls in other environments that we're not supporting them in so I certainly think yeah, really important to involve those people that are most involved with the client really… we certainly we have people that attend work placements and you know college placements, day services, that sort of thing so I think you know what happens in one of them impacts on what happens in another so yeah, I think you would want to see that sort of follow-through of any kind of actions you're taking at home. It might need to be replicated somewhere else'(CAR002) '…it could be used in different settings, day centres with carers who know the person very well, so yeah it could be used across settings…'(HCP010-OT)
Incorporate form into existing care systems	Incorporate programme into existing documentation and processes, for example, care plans, annual health check	'I suppose maybe some of that should be in a health action plan as well'(HCP006-PT) 'If you got the doctors to send it yearly with their medical check and complete the form before they come in, then I think a lot of them would do it'(CAR007) 'if we were to implement it here, we would have it in line with annual health assessments…'(CAR001)

adult sibling). One carer interview was conducted in person at a local hospital with the remaining interviews conducted remotely over phone or video call.

- Ten AWID took part in a group interview conducted over three visits and three AWID took part in individual interviews which were conducted over two visits. Two group facilitators were present during the group interview. The group interview was conducted face to face at a community venue. The individual interviews were conducted face to face at the participants' residence with a carer present.

Due to the method of recruitment through professional networks and established groups and clinical systems, the number of potential participants who were invited to take part that did not respond is not known. No participant dropped out once they had met to discuss the research and consented to take part.

Key themes

Five key themes were identified in the final framework with subthemes within each theme. These are summarised below. Interview participants also commented on the specific content of each of the risk factors included in the programme (eg, epilepsy, medications) suggesting wording changes or changing the order of presentation. Detailed presentation of this data is beyond the scope of this paper.

Theme 1: programme approach

A summary for the theme 'programme approach' is presented in table 1.

HCP identified a need for a 'standardised' approach, such as the ACTiON FALLS LD programme. The HCP stated that this could be used nationally to ensure a consistent approach and equity in provision. The need for the programme to support educating HCP, carers and AWID in the reasons why someone might fall and what actions can be taken to reduce these risks as much as possible were highlighted. The importance of considering differences in how risks are perceived by HCP, carers and AWID was identified with an acknowledgement that risk perception is subjective and influenced by factors such as context, environment and cognition.

Theme 2: programme delivery

A summary for the theme 'programme delivery' is presented in table 2.

Delivery of the programme was considered in the interviews primarily by HCP and carers. The difficulties of transition points from child to adults' services in managing conditions for AWID was identified as well as the provision of non-specialist services into adulthood. Considering how the programme could be integrated into existing care systems such as annual health checks was expressed. The need for the programme to be flexible to allow it to be used in different ways across different settings and services emphasised the different settings and services where AWID are supported.

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Table 3 Summary of who would be involved in the programme

Subtheme	Description	Supporting evidence
Inclusion of carers	Importance of including family members and carers and designing the programme to maximise their inclusion	'…I would have it in simple 'plain English and I would say what's it for and why are you talking about falls"(CAR003) '…carers can often tell professionals what they think might work or not, because professionals are great at coming up with the most amazing action that they know for the average person will work really well, but they need to give the carer the opportunity to say well actually that's probably not going to work because of these kinds of issues with this person's life' (HCP007-RN) Care staff would help complete form (AWID002)
Inclusion of AWID	Need for a component of the programme that allows AWID to be meaningfully included to facilitate engagement, ownership and independence	AWID Group Interview: To be consulted as group felt often decisions about them are made without them AWID Group Interview: Felt that they were treated like 'normal' people in being included in the research process 'Getting the individual to come up with those goals themselves' (HCP013-OT) Would like space for own view (AWID001)
Specialist clinician	Role of specialist clinician in completing a detailed falls assessment and the need for training to support this	'…I think at some point it kind of becomes a very specialist tool that needs to be filled in by that specialist' (HCP001-PT) 'it would be down to are they confident in effectively communicating with somebody with a learning disability ….it would have to be completed by someone who would be able to know how to take all of that really useful information and make it applicable to someone with a learning disability(HCP013-OT)
Multidisciplinary team (MDT) approach	Importance of encouraging an MDT approach to a multifactorial problem	'…could certainly complete or complete in collaboration with OT [occupational therapist] and physio'(HCP012-OT) 'I feel like at the moment it is a very much a physiotherapy—seen as a physiotherapy issue solely, falls, which I'm quite keen to challenge in that it should be a multidisciplinary approach'(HCP009-PT) 'That's what I'm thinking. So it can be used as a generic form, that form—If I'm the first one in contact with the, after the referral, if I'm the first one dealing with that referral, as a physio I will be able to do that, and then I will expect that form can be used by the nursing and the occupational therapist members as well'(HCP003-PT) 'I think the tool itself is simple enough for a professional to pick up and to work through with an individual.' (HCP005-SLTA) '…actually this would make me really happy—to go with it, a small short, as a separate document, full screening the members of the wider MDT could take out to assessments with them to complete and then depending on what was ticked on that full screening, that would then trigger an onward referral to us'(HCP011-PT) 'Falls are everybody's business…'(HCP014-OT)

AWID, adults with an intellectual disability.

Theme 3: who would be involved in the programme

A summary for the theme 'who would be involved in the programme' is presented in table 3.

AWID strongly emphasised the importance of their involvement in the programme and their care decisions often feeling decisions were made without them. Carers also expressed the importance of the programme being accessible for them as well as the content reflecting their role in the management of falls as they may well know what works well in different contexts.

The physiotherapists included in the interviews highlighted the importance of the programme in encouraging a multidisciplinary approach to falls management and that the design should support completion by any healthcare profession. This contrasted with views around needing specialist skills and training in intellectual disability care to support effective completion of the programme.

Theme 4: programme design

A summary for the theme 'programme design' is presented in table 4.

Designing an appropriate programme was the primary focus of the discussions. All stakeholders voiced the importance of designing a programme that was accessible for AWID, using a variety of information sources to present the information to meet a range of needs.

The value of a proactive approach that allows falls risks to be considered before a fall has happened was raised by HCP and carers, however, it was also important that the programme responded reactively to changing needs and after a fall has happened.

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Table 4 Summary of programme design

Subtheme	Description	Supporting evidence
Personalisation	Encouraging action through collaboratively developing a creative personalisation of programme and personal action plan	'I think you can make that more individualised to that person'(HCP009-PT) '…encourage curiosity, make personable to engage them'(CAR008-Researcher Field Notes) AWID Group Interview: Need a larger space to write to have option to put own views on the form Like it in colour ideally sparkly pink (AWID002)
Proactive approach that facilitates timely action	Programme needs to be dynamic to support proactive and long-term management of falls and supports the identification of AWID who may not recognise health needs	'I think maybe if they have several falls, in three or twelve months or whatever, then maybe doing something like this that's much more detailed might be more relevant at that point. But then you think well does it have to get to this point before you sort of intervene'(HCP004-OT) 'There's probably individuals out there living independently in the community that might be falling that aren't necessarily reporting those as falls …. and if that person's not able to tell us, obviously that can be a barrier'(HCP005-SLTA) 'Something that's going to be useful long term, because the other thing about I think carers is they just get fed up with how things change all the time and actually they get used to something and then somebody throws that document away and they go 'oh it's this document now'(HCP007-RN) '…we're all getting older and we perhaps view each other as the same age as when we first met and we're not. We're twenty years older than we were and have perhaps slowed down a little or aren't as physically capable as we once were'(CAR001)
Accessibility	Programme design needs to be accessible to support AWID engagement with varied information sources as no one approach will suit everyone	AWID Group Interview: personalised photos for example, of places would help engagement … but don't make it so simple that it doesn't do its job—'you either get it or you don't' '…making the information accessible for people with learning disabilities, helping to support their understanding of the questions that you're answering but also to be able to express themselves in a meaningful way'(HCP005-SLTA) AWID Group Interview: Symbols can be mis-interpreted and not understood
Detailed versus generic	Sufficient detail to be useful and informative but not overwhelming	'…the problem with some of these assessment tools is that they need all the detail, don't they, and then trying to make them so much shorter you lose some of that information and that is just making sure that they're done by the right people I suppose in terms of the professional work that's got the time to find out all that information'(HCP001-PT) ' …when we present with anything that's got too much words or is a bit wordy or there's too much going on and even with care staff who only have a limited period of time with the client, so they think oh blimey I've got all this to fill in'(HCP002-PT) 'well if you make it too short you're not going to cover enough questions really, you know, you're not going to get that breadth of information that's really valuable'(HCP006 -PT)
Flexibility in format	Options of paper and digital format for staff to adapt and optimise appropriate interaction with clients and work within current clinical systems	'I think different formats would be useful, so I think having something like a version in Microsoft Word that could be typed into from a tablet or a laptop would be enjoyed by some people. Equally just being able to have it on paper, printed out, works for others.'(HCP011-PT) 'Both—digital can increase independence with completion for example, if reduced writing ability- but still gets it checked' [Researcher Field Notes] 'A lot of them were saying they couldn't afford credit on their phone or they couldn't afford—can Wi-Fi?'(CAR003) AWID Group Interview: Video to view on phone/interview to access information, make as accessible as possible with subtitles and for the video to broken up
Terminology	Consideration of appropriate terminology and title of the programme	'…think you have to go with the 'intellectual development disability' because that's the wording and the phrasing that we use now. I think we're all becoming very familiar with that and we're all getting used to saying that now'(HCP005-SLTA) 'I think that people with a learning disability won't necessarily have heard the phrase intellectual disability. So I—and probably throughout their life they would have had the term learning disability used because of children's learning disability team and within schools—I think I prefer learning disability just because I feel that that's what's known'(HCP009-PT) 'I would say learning disabilities because I have a bit of reasoning for that as well. I started off by saying intellectual disabilities and the more feedback I got was that ID seems to be a bit more American and LD is what we use more in this country. So that's what I decided to go with based on feedback'(HCP013 -OT) AWID Group Interview: Don't use medical terminology

Continued

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Table 4 Continued

Subtheme	Description	Supporting evidence
Ownership	Encourage appropriate responsibility and ownership of the programme	'I think being very clear about what your actions are in the language that somebody understands or somebody else in the room understands, then they can then kind of—and to encourage people with learning disability to hold you to account'(HCP007- RN) AWID Group Interview: Would be able to complete but that they would get checked
How to deliver and sustain the programme	Consideration over how to deliver and sustain falls management programmes	'I think the other part of the challenge is then how you deliver falls intervention, so I think if you're looking at the things like the Tinetti Falls Programme, which is really well evidenced in an older population, people with a learning disability don't tend to get that… so you need to be quite inventive with your treatment techniques'(HCP001-PT) "If we are kind of sharing kind of new resources, new information, that sort of thing, we would always offer sessions of some sort'(CAR002)

AWID, adults with an intellectual disability.

There was tension around the level of detail to include in the programme in order to make it meaningful without it becoming too long to be practically useful.

There was conflict between HCP views on appropriate terminology with suggestions that intellectual disability is now the preferred term contrasted with views that learning disability is the more well-known term used outside of research.

Theme 5: programme components

A summary for the theme 'programme components' is presented in table 5.

There was a clear need for different components of the programme—a screening tool and clinical assessment to be used with support from clinical service as well as a need for specific resources for AWID and carers that can be used without any clinical input. The need for the programme to facilitate appropriate actions and clearly indicate a personalised action plan was raised by HCP and carers.

DISCUSSION

Summary

This qualitative study aimed to explore experience and views from key stakeholders involved in falls management for adults with AWID. The interview study has explored how to adapt the ACTiON FALLS LD programme based on the views of 14 HCPs, 8 carers and 13 AWID. Framework analysis identified five key themes: programme components, programme design, programme approach, who would use the programme and programme delivery. The importance of a national standardised approach to falls management to ensure equity for AWID was identified, however, the programme also needed to be flexible to meet individual needs. Considerations of how the programme can be integrated into existing systems and processes as well as how it can encourage a proactive approach to falls management were identified. The importance of meaningfully including AWID in the completion and decision-making of their care was highlighted.

Participants reviewed the ACTiON FALLS LD programme to assess its relevance to AWID and identified areas where the programme needed to be adapted for AWID. These included developing two individual components that could work together or be used separately. One component aimed at AWID and carers to raise awareness of falls risks and support including the views and preferences of AWID and one component aimed at HCP to guide actions to reduce falls risk. The tool needs to be adapted to be flexible and acknowledge the differences in the perception of risks between AWID, carers and HCP. Anxiety and fear of falling should be included as a clear risk factor within the tool.

Strengths and limitations

The study had several strengths and limitations. The interview approach for AWID was developed in collaboration with AWID to maximise inclusivity and support meaningful participation. Group and individual interviews were offered and conducted over several visits to develop rapport and trust. A range of methods to support discussions (eg, case studies, drawing ideas) was used and was welcomed by participants. By using these approaches, the views expressed by AWID are more likely to be reflected through increased understanding and opportunities.

While efforts were made to recruit a range of HCP, not all HCP involved in the management of falls were included (eg, dietitians, general practitioners), which may have limited the views explored. The type of HCPs volunteering to take part (primarily physiotherapists and occupational therapists) may however reflect the primary professionals currently involved in falls management.

The definition of a carer was deliberately broad to reflect the range of services and organisations that support AWID in community setting. Although a range of carer views were explored, for example, family carers and carers working in social and education settings, this could have led to difficulty in adapting the programme to account for this range of views.

The researcher undertaking the interviews was a registered physiotherapist and the study team included

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Table 5 Summary of programme components

Subtheme	Description	Supporting evidence
Screening tool and clinical assessment	The programme should include a detailed clinical assessment with a screening/triage tool to allow AWID to give their views	'…could be like sent out to the patient in the post maybe and asked to complete sort of a bit like a pre-op pre-screening type tool type thing, that could be done at home, because it's a bit more kind of relaxed I believe, whereas part 2 could be filled in in like a session with a health professional maybe by the staff member.'(HCP013-OT) '…you might have a tool that has something in the background that kind of helps the professional with some of the more complicated issues, but then the foreground of that is something that somebody with a learning disability or their carer can understand'(HCP007- RN) AWID Group Interview: Having opportunity to explain their view about falls was helpful and helped facilitate communication with their families about falls
Resources for AWID and carers	Importance of supporting resources to provide awareness raising and information for AWID and carers	'have almost a booklet that says this is what I can do to help reduce me falling? (HCP002-RN) 'Making an appointment, waiting 18 months for it to be told you need to go and do this next, then come back to me because you're looking at a three year wait before you have the initial conversation. If you can just proactively achieve the things that you know are going to be on a tick list of check this, check this, check this, it speeds the whole process up.'(CAR001) 'I think having….something like really easy to pick up and read, like a leaflet, with useful numbers that they can call if they need additional support, would be helpful as well…(HCP010-OT) '…to say watch the video, it'll give you some ideas about what you need to think about, so you don't then necessarily need to have it all in the text. I think you know people open things and if there's lots of text and it looks unwieldy, then people won't fill it in'(CAR002) 'But I guess there would need to be something, some explanatory note about why, what's the value of collecting the information, so like what would the outcome be.'(CAR002)
Suggested actions	How to achieve a proportionate, appropriate response to identified risk for the individual	AWID Group Interview Researcher Filed Notes: Be aware that 'well meaning' amendment of environment could in itself be a falls risk 'quite often it's looking at the risks of behaviours or the incidence of unpicking that and then possibly if it's something—you get a lot of falling out of bed and then you get a big rush of everybody wanting bedrails and hospital beds, and it's trying to kind of look at the pros and cons, and actually the deprivation of liberty angles and things like that, and looking at what other things you can try. And having a moderate response rather than going straight in with quite a restrictive response. But then at the same time, not wanting to wait for something catastrophic to happen before you do anything at the same time. So it's a bit of a balancing act really '(HCP004-OT) AWID Group Interview: Range of things that could help include using humour, repeating an activity and using visual strategies including finding pictures the steps to complete tasks
Inclusive communication plan	Programme to include a communication needs plan to facilitate completion	'Quite a lot of people with a learning disability have been seen through the speech and language therapy service so there's some sort of communication guidelines, or quite often if there's homes that people live in, there will be some kind of documentation about what the person's understanding is like, what their expressive communication is like. So I think for the individuals that are doing that, doing the questionnaire, having that little bit of information at hand would be really useful so you're knowing where to pitch your communication skills to them'(HCP005-SLTA)
Action plan	Programme to include a clear action plan	'…they'll have a really clear idea of what they need to do and then they can prioritise. I mean they want to—perhaps write them out in the order of priority, because there might be quite a lot of actions '(HCP010-OT) '…to support people with learning disabilities to understand what to do if they have had a fall' '….that they have an idea and maybe the form can also tell them who to contact for what'(CAR002)

AWID, adults with an intellectual disability.

physiotherapists and occupational therapists. Members of the study team with different backgrounds (physiotherapists, occupational therapists, psychologists) were involved in the development and evaluation of the original ACTiON FALLS programme.We acknowledge that the experience and professional expertise of the study team may have influenced the scope and focus of the interviews as well as the analysis and interpretation.

Wider context

Barriers to accessing appropriate and timely healthcare for AWID are well documented with AWID experiencing poorer health than the general population.[15] This inequity in provision and support was recognised by the HCP and carers in this study emphasising the importance of providing equity in falls management for AWID.

The need for a standardised, consistent approach to falls management that supports AWID in specialist and generic services was highlighted underlining the need for adapting the ACTiON FALLS LD programme. An action plan to build the right support for AWID was published by the UK Government in July 2022 detailing a commitment to keep AWID safe, provide personal care and support and promote inclusive decision-making.[16] These principles are in line with the principles of the ACTiON FALLS LD programme in reducing and managing falls risks through a personalised approach with AWID at the centre of the decision-making. This was also supported by views of AWID who wanted to be involved in the programmes designed to support their care and to be more involved in decisions about themselves. The adaption of the ACTiON

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FALL programme has been underpinned by the inclusion of the views and preferences of AWID demonstrating a strength in this research in supporting inclusion from the start.

There were contrasting views of whether specialist clinical knowledge was needed to complete the programme. This might be due to differences in perceptions of required competencies between healthcare professions with more specialised clinicians regarding their particular skill set as essential for the programme. This assumption should be confirmed in further research.

Although many of the risk factors for falling are common across the general older population and AWID, the views expressed in this study have highlighted some areas, which are of particular concern to AWID. The differences in how risks are perceived between AWID, carers and HCP were discussed with the acknowledgement that risk perception is a subjective process. In previous qualitative research by Cahill *et al*,[1] carers expressed their views that AWID may have decreased hazard awareness and therefore not identify or act on a potential falls risk. These differences in risk perception and hazard awareness may require a flexible and dynamic approach where the views of AWID and carers are regularly discussed and reviewed.

Environmental factors relating to falls risks were highlighted as important to consider within the programme and a recent scoping review of risk factors for falls for AWID reported falls were most likely within the home environment and often in bathrooms, toilets and bedrooms.[17] Concerns were, however, expressed by some AWID about navigating obstacles in new environments and this could potentially lead to a reduced confidence in going out. The implications of not going out could include social isolation as well as reduced independence, mobility and the ability to carry out daily tasks. A recent cohort study by Choi *et al*[18] identified dependency with activities of daily living to be a key predictor of falls for AWID suggesting that carers and professionals need to 'closely monitor' individuals who require this support. The balance of supporting activity while minimising risk is however a key challenge in all falls management to ensure independence is maximised.

There was a lack of agreement between the stakeholders in this study on the most appropriate terminology to use with the ACTiON FALLS LD programme. Intellectual disability is now the commonly used term across research[19] with a suggestion this can reduce the confusion with the term learning difficulty, which refers more to conditions such as dyslexia.[20] Further work is needed to explore the views of AWID and carers on the most appropriate terminology to use within the programme.

Research implications

Undertaking this qualitative study has identified barriers to inclusion in research for AWID using traditional research processes and methods. Easy read documentation is appropriate for some participants, however, it does not support all AWID with different needs. An increased awareness for researchers on the challenges faced by AWID as well as strategies to support inclusion is needed. In addition, further research is needed to explore creative approaches that support AWID to engage meaningfully in research and to ensure their inclusion is not tokenistic.

This study has identified areas where the ACTiON FALLS LD programme needs to be adapted for AWID which forms the next stage of this programme of research. This includes further developing the two components—one targeted at AWID and carers to raise awareness of falls risks and to capture the thoughts and preferences of AWID and one targeted at HCP where falls risk factors are assessed and actions taken. Consideration of how the two components can work together or be used separately was highlighted. Exploration of how to develop both components to be accessible in an electronic format was indicated.

Conclusion

This qualitative interview study has explored the views of AWID, HCP and carers to identify how to adapt the ACTiON FALLS LD programme for AWID. In adapting the programme, it is important to consider the impact of difference in risk perception, fear of falling and anxiety surrounding change for AWID. The programme needs to be accessible and support the inclusion of AWID in managing falls and ultimately fulfil the requirement to be a proactive and educational tool for all.

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Competing interests PL was the lead of the Falls in Care Homes trial and led the development of the ACTiON FALLS programme for community and care home settings, KR was a researcher on the Falls in Care Homes trial.

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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