

The experience of type 2 diabetes self-management in adults with intellectual disabilities and their caregivers: a review of the literature using meta-aggregative synthesis and an appraisal of rigor

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Table 1: Summary of studies

Study	Aims/design/method	Participant characteristics
Rey-Conde et al. (2005) Australia	Exploring perceptions from PWID and caregivers. Qualitative study using focus groups	<p><i>N</i> = 67: PWID (<i>N</i> = 9); Family members (<i>N</i> = 8); Paid caregivers (<i>N</i> = 31); Service coordinators (<i>N</i> = 12); Health professionals (<i>N</i> = 6); Sector worker (<i>N</i> = 1); Living status: Living at home (<i>N</i> = 3); Supported accommodation (<i>N</i> = 6); Further demographics not provided</p>
Hale et al. (2011) NZ	Exploring knowledge and understanding of PWID self-managing T2D. Interviews analyzed using the General Inductive approach	<p><i>N</i> = 14 adults with ID Age: Mean: 51 years Ethnicity: Maori (<i>N</i> = 3); New Zealand European (<i>N</i> = 11) Gender: Female 43% Level of disability: Mild (<i>N</i> = 11); Moderate (<i>N</i> = 3) Living status: Residential care (<i>N</i> = 11);</p>

		<p>Supported independent living (<i>N</i> = 2); Independent living (<i>N</i> = 1) Diabetes type: Type 1 (<i>N</i> = 6); Type 2 (<i>N</i> = 8) Management approach: Not specified Time since diagnosis: 2-5 years (<i>N</i> = 3); 6-10 years (<i>N</i> = 4); 10+ years (<i>N</i> = 7)</p>
Dysch et al. (2012) UK	<p>Exploring experiences and perceptions of people with ID and diabetes. Qualitative study using IPA</p>	<p><i>N</i> = 4 Adults with ID Age: Mean 35 years Ethnicity: Not specified Gender: Female 75% Level of disability: Mild Living Status: Residential care (<i>N</i> = 2) With family (<i>N</i> = 1) Independent (<i>N</i> = 1) Diabetes type: Type 1 (<i>N</i> = 2); Type 2 (<i>N</i> = 2) Management approach: Not specified</p>

Time since diagnosis:
Mean 17 years

Cardol et al. (2012a)	Exploring T2D self-management experiences of PWID.	<p>N = 17 adults with ID</p> <p>Age: mean 52 years</p> <p>Ethnicity: Not specified</p> <p>Gender: Female 53%</p> <p>Level of disability: Mild (<i>N</i> = 7); Moderate (<i>N</i> = 7); Unknown (<i>N</i> = 3)</p> <p>Living status: Independent living with and without support (numbers not given)</p> <p>Diabetes type: Not specified</p> <p>Management approach: Diet alone (<i>N</i> = 3) Medication (<i>N</i> = 6) Insulin (<i>N</i> = 8)</p> <p>Time since diagnosis: Under 5 years (<i>N</i> = 5); 5+ years (<i>N</i> = 12)</p>
Netherlands	Qualitative study using Leventhal's (1997) Illness Perception Framework and Thematic Analysis	
Cardol et al. (2012b)	Exploring views of caregivers of PWID who have T2D.	<p>N = 13 caregivers</p> <p>Age: Mean 52 years</p> <p>Ethnicity: Not specified</p> <p>Gender: 72% female</p>
Netherlands		

Trip et al. (2015)	Exploring the role of key workers in supporting PWID self-managing T2D. Qualitative study using Thomas' General Inductive Approach	<p><i>N</i> = 17 Support staff</p> <p>Age:</p> <p>18-30 (<i>N</i> = 3);</p> <p>41-50 (<i>N</i> = 1);</p> <p>51-60 (<i>N</i> = 4);</p> <p>60+ (<i>N</i> = 9)</p> <p>Ethnicity:</p> <p>New Zealand European (<i>N</i> = 14);</p> <p>Maori (<i>N</i> = 1);</p> <p>Australian (<i>N</i> = 1);</p> <p>African (<i>N</i> = 1)</p> <p>Gender:</p> <p>Female 88%</p>
NZ		
Whitehead et al. (2016)	Exploring the experiences of PWID and their caregivers self-managing T2D with a focus on the practice of autonomy	<p><i>N</i> = 31</p> <p>PWID (<i>N</i>=14)</p> <p>Age:</p> <p>Mean 51 years</p> <p>Gender:</p> <p>Female 43%</p> <p>Ethnicity:</p> <p>Not specified</p> <p>Level of disability:</p> <p>Mild (<i>N</i> = 11);</p> <p>Moderate (<i>N</i> = 3)</p> <p>Living status:</p>
NZ		

		<p>Independent living (<i>N</i> = 1) Supported living (<i>N</i> = 2) Residential care (<i>N</i> = 11) Diabetes type: Type 1 (<i>N</i> = 6) Type 2 (<i>N</i> = 8) Management approach: Diet alone (<i>N</i> = 1) Medication (<i>N</i> = 8) Insulin (<i>N</i> = 5)</p> <p>Time since diagnosis: Not specified:</p> <p>Caregivers (<i>N</i> = 17) Age: 18-30 (<i>N</i> = 3); 41-50 (<i>N</i> = 1); 51-60 (<i>N</i> = 4); 60+ (<i>N</i> = 9) Gender: Female 88% Ethnicity: Not specified</p>
Rouse and Finlay (2016)	Discourse analysis of the concept of responsibility in people with ID and their caregivers self-managing T2D	<p><i>N</i> = 14 PWID (<i>N</i>=7) Age: 20-54 Gender: Female 71%</p>

Ethnicity:
Not specified
Level of disability:
Mild-Moderate (*N*=7)
Living status:
Not specified
Diabetes type:
Type 1 (*N* =2)
Type 2 (*N* = 5)
Management approach:
Not specified
Time since diagnosis:
"At least 6 months prior to interview"
Caregivers (*N* = 7)
Age:
44-51
Gender:
Female 71%
Ethnicity:
Not specified

Table 2: Findings and plausibility

Study	Finding	Plausibility
Rey- Conde et al. (2005)	People with ID's perception of diabetes self-management (DSM) barriers expressed as negative feelings	Unequivocal: Clear transcript excerpt
	People with ID spoke about practical DSM experiences and abilities	Unsupported: Stated as frequent but number of participants not provided
	People with ID proud of skills, though these were limited	Equivocal: Transcript excerpt does not illustrate pride or limits
	Negative responses to question on what is easy about DSM	Unequivocal: Clear transcript excerpt and observations
	Acknowledgement of dependence on families and support staff	Unequivocal: Clear transcript excerpt and number
	People with ID made positive comments about exercise	Unequivocal: Clear transcript excerpt
	Concern and conflict in diet but some positive choices	Equivocal: Transcript excerpt but number of participants not stated
	Families and support staff felt that cognitive limitations were the biggest barrier but tailored education could help	Equivocal: Frequent observations but no excerpt
	Staff training was a barrier to DSM	Unequivocal: Clear transcript excerpt and frequencies
	Staff skills were mainly in observations and taking blood sugar levels	Equivocal: Transcript excerpt only partially illustrates
Prompts, diet management and planning works well	Equivocal: Frequency observations	

	Exercise is limited. Walking and bowling are most common	Equivocal: Transcript excerpt does not clearly illustrate
	Lack of motivation and preferences are seen as barriers for people with ID	Equivocal: Transcript excerpt but number of participants not stated
	More information on diet is needed	Equivocal: Transcript excerpt limited and number of participants not stated
	Fear and insecurity in staff over supporting DSM	Equivocal: Transcript excerpt but number of participants not stated
Hale et al. (2011)	Three levels of knowledge and understanding of diabetes in people with ID: good, limited and basic	Unequivocal: Clear transcript excerpts and participant numbers
	Blood Sugar Levels were not fully understood by people with ID but symptoms of blood sugar changes were recognised	Equivocal: Transcript excerpt but number of participants not stated
	Diet awareness limited to avoiding sugar and difficult to monitor outside of residential care	Unequivocal: Clear transcript excerpts and participant numbers
	Information provision was limited or not in accessible formats	Unequivocal: Clear transcript excerpts and participant numbers
	Participants were good at remembering to monitor blood sugar levels but needed support	Equivocal: Transcript excerpt but number of participants not stated

	Participants were aware that walking was good for DSM and that have a walking “buddy” would help with this	Equivocal: Transcript excerpt but number of participants not stated
	Most support came from residential carers. Numbers of diabetes care plans were limited and some staff were unaware these existed	Equivocal: Researcher observation of care practice but
	Frustrations from some participants over lifestyle restrictions	Equivocal: Transcript excerpts but number of participants not stated
Dysch et al. (2012)	Participants showed understanding through language related to diabetes	Unequivocal: Transcript excerpts and number clear due to sample size
	Confusion and over diabetes	Unequivocal: Transcript excerpts and number clear due to sample size
	Participants described the fluctuating state of having diabetes	Unequivocal: Transcript excerpts and number clear due to sample size
	Participants described the physical effects of diabetes	Unequivocal: Transcript excerpts and number clear due to sample size
	Frustration with lifestyle adjustments	Unequivocal: Transcript excerpts and number clear due to sample size
	Struggling with adherence to DSM	Unequivocal: Transcript excerpts and number clear due to sample size

	Preparation and planning relating to DSM	Unsupported: Excerpts did not clearly relate to diabetes
	Diabetes as tolerated	Equivocal: Transcript excerpts but number of participants not stated
	Diabetes was unwanted	Unsupported: excerpts do not differentiate from “Frustrations” sub-theme
	Support from others required for DSM	Equivocal: Transcript excerpts do not always describe DSM
	Participants struggle with the need for support	Equivocal: Transcript excerpts but number of participants not stated
	Social stigma of diabetes and DSM	Equivocal: Transcript excerpts but number of participants not stated
	Social comparisons aid understanding of diabetes	Equivocal: Transcript excerpts but number of participants not stated
	Social interaction impeded by diabetes	Unsupported: excerpt does not clearly relate to DSM
	Participants reported multiple health difficulties	Unequivocal: Clear transcript excerpts and participant numbers
Cardol et al. (2012a)	Feelings with loss regarding food and choice	Equivocal: Transcript excerpts clear but number of participants not stated
	Feelings of loss of food choice through social comparison	Equivocal: Transcript excerpts but number of participants not stated

Medication control: mixed understanding and anxiety	Equivocal: Transcript excerpts but number of participants not stated
Not feeling ill: diabetes only perceived as serious when insulin injections are required	Equivocal: Transcript excerpts but number of participants not stated
Multiple illnesses make diabetes symptoms hard to understand	Unsupported: No excerpts or frequencies
Fear and uncertainty over diabetes consequences	Equivocal: Transcript excerpts but number of participants not stated
Check-ups without questions	Unsupported: excerpts do not clearly describe theme
Participant's had practical but limited knowledge of dietary restrictions	Equivocal: Transcript excerpts but number of participants not stated
Relationship between understanding of diabetes and DSM	Equivocal: Transcript excerpts but number of participants not stated
Lack of tailored resources available	Unsupported: No excerpts, or frequencies
Motivation is more important than level of ID	Unsupported: No excerpts or frequencies
DSM relaxed during special occasions	Unequivocal: Transcript excerpts clear and all participants included
DSM is related to self-confidence	Equivocal: No excerpts but observations which summarize data are clear

	Opportunities to build self-confidence were limited	Equivocal: No excerpts but observations which summarize data are clear
	Family members are important for support and feedback	Equivocal: Transcript excerpts but number of participants not stated
	Participants' mood can make DSM difficult	Unsupported: No excerpts, observations, or frequencies
	Financial restrictions can impede DSM	Equivocal: Transcript excerpts but number of participants not stated
	Communal living arrangements can impede DSM through social comparison	Unsupported: No excerpts, observations, or frequencies
Cardol et al. (2012b)	Caregivers did not perceive the seriousness of diabetes	Unequivocal: Clear transcript excerpts and participant numbers
	Compassion but concern over competence in DSM	Unequivocal: Clear transcript excerpts and participant numbers
	Lack of motivation for DSM regarded as dispositional in people with ID	Equivocal: Transcript excerpts but number of participants not stated
	Levels of training were varied: nurses were better qualified and caregivers sought help from doctors	Equivocal: Transcript excerpts and based on observations
	Diabetes was not a prominent feature in care unless insulin injections required	Equivocal: Transcript excerpts but number of participants not stated
	Differences between caregivers in level of support for autonomy	Equivocal: Transcript excerpts but number of participants not stated

	Dilemmas between enabling autonomy and safeguarding health-care using creative solutions	Equivocal: Transcript excerpts but number of participants not stated
Trip et al. (2015)	Key-worker knowledge and understanding: diabetes management varied and limited	Unequivocal: Clear transcript excerpts and participant numbers
	Key-worker knowledge and understanding: Caregivers could recognise that behavioural changes may reflect diabetes symptoms	Unequivocal: Clear transcript excerpts and participant numbers
	Key-worker knowledge and understanding: knowledge of impact of comorbidities was varied and limited	Unequivocal: Clear transcript excerpts and participant numbers
	Lifestyle police: caregivers felt personally responsible for the health status of people with ID and focussed on controlling dietary intake	Unequivocal: Clear transcript excerpts and participant numbers
	Frustration over lack of consistency in care	Unequivocal: Clear transcript excerpts and participant numbers
	Caregivers recognise that training needs are ongoing but are unsure what was required	Unequivocal: Clear transcript excerpts and participant numbers
	Nurturing self-management skills: creating opportunities to check understanding and providing education on shopping, cooking and menu planning, though this was limited by time	Unequivocal: Clear transcript excerpts and participant numbers

Whitehead et al. (2016)	Daily negotiated autonomy in relation to blood glucose: Support needed to record data	Unequivocal: Clear transcript excerpts and participant numbers
	Daily negotiated autonomy in relation to medication: Participants were almost fully independent with occasional support	Equivocal: Transcript excerpts but number of participants not stated
	Daily negotiated autonomy in relation to insulin injections: Participants were almost fully independent with occasional support	Equivocal: Transcript excerpts but number of participants not stated
	Dietary choices described as negotiated, ongoing and supported	Equivocal: Transcript excerpts but number of participants not stated
	Relationships and trust facilitated diabetes negotiated autonomy	Equivocal: Transcript excerpts but number of participants not stated
	Caregivers were aware of risks versus autonomy	Equivocal: Transcript excerpts but number of participants not stated
	People with ID were supported to be autonomous during medication adjustments but control was sometimes increased during these times, then readjusted accordingly	Equivocal: Transcript excerpts but number of participants not stated
	Renegotiation of autonomy in relation to goals: healthier diet	Equivocal: Transcript excerpts but number of participants not stated
	Renegotiation of autonomy in relation to goals: living arrangements and diet	Equivocal: Transcript excerpts but number of participants not stated

Rouse and Finlay (2016)	Repertoires of confidence in relation to recognising symptoms	Unequivocal: Clear transcript excerpts and participant numbers
	People with intellectual disabilities as described as themselves competent in relation to DSM	Unequivocal: Clear transcript excerpts and participant numbers
	People with intellectual disabilities as lacking specific competence in relation to DSM tasks including organising, remembering and meal preparation	Unequivocal: Clear transcript excerpts and participant numbers
	Caregivers described as intervening to support partial competence	Equivocal: Transcript excerpts but number of participants not stated
	Repertoires of partial competence were more frequently drawn upon by paid supporters	Equivocal: Transcript excerpts but number of participants not stated
	Repertoires of incompetence were more frequent in interviews with family supporters	Equivocal: Transcript excerpts but number of participants not stated
	Lack of competence was often described as due to internal factors by caregivers	Unsupported by transcript excerpt

	Constructing a positive identity: participants with ID described the needs for support but defended themselves against being seen as incompetent	Equivocal: Transcript excerpts but number of participants not stated
	Lack of competence was often described as due to external factors by people with ID, such as the attitudes of doctors	Equivocal: Transcript excerpts but number of participants not stated
	People with ID construct themselves as 'lazy' to defend against being seen as disabled	Equivocal: Transcript excerpts but number of participants not stated
	Health care professionals are positioned as being competent in a broad sense, holding a higher level of diabetes knowledge	Equivocal: Transcript excerpts but number of participants not stated
	Dilemmatic repertoires were presented regarding people with ID's independence	Unequivocal: Clear transcript excerpts and participant numbers
	Repertoires of risk management and control presented dilemmas against independence	Equivocal: Transcript excerpts but number of participants not stated
	Responsibility and accountability are constructed as shared and problematic	Equivocal: Transcript excerpts but number of participants not stated

Table 3: Synthesis of findings

Finding	Category	Synthesised finding
People with ID's perception of diabetes self-management (DSM) expressed as negative feelings (U); (Rey-Conde et al., 2005)	Negative feelings regarding having diabetes	Frustration over lifestyle adjustments
Frustrations from some participants over lifestyle restrictions (E); (Hale, 2005)	Frustration over diabetes related lifestyle changes	
Frustration with lifestyle adjustments (E); (Dysch et al., 2012)		
Struggling with adherence to DSM (E); (Dysch et al., 2012)		
Participants struggle with the need for support (E); (Dysch et al., 2012)		
Feelings with loss regarding food and choice Cardol et al. (E) (2012a)	Feelings of loss following diabetes related lifestyle changes	
Feelings of loss of food choice through social comparison Cardol et al. (E) (2012a)		
Social stigma of diabetes and DSM (E); (Dysch et al., 2012)	Impact of social setting	
Financial restrictions can impede DSM (E); (Cardol et al., 2012a)		
Social comparisons aid understanding of diabetes (E); (Dysch et al., 2012)		

Finding	Category	Synthesised finding
Acknowledgement of dependence on families and support staff (U); (Rey-Conde et al., 2005)	Limited competencies and dependence on caregivers	Limited understanding and inadequate educational resources
People with intellectual disabilities as lacking specific competence in relation to DSM tasks including organising, remembering and meal preparation (U) (Rouse and Finlay, 2016)		
Diet awareness limited to avoiding sugar and difficult to monitor outside of residential care (U); (Hale et al., 2005)		
Compassion but concern over competence in DSM (U); (Cardol et al., 2012b)		
Support from others required for DSM (E); (Dysch et al., 2012)		
Three levels of knowledge and understanding of diabetes in people with ID: good, limited and basic (U); (Hale et al., 2005)	Understanding is limited leading to limited DSM skills	
Confusion over diabetes (E); (Dysch et al., 2012)		
Exercise is limited. Walking and bowling are most common (E); (Rey-Conde et al., 2005)		
Medication control: mixed understanding and anxiety (E); (Cardol et al., 2012a)		
Not feeling ill: diabetes only perceived as serious when insulin injections are required (E); (Cardol et al., 2012a)		
Fear and uncertainty over diabetes consequences (E); (Cardol et al., 2012a)		
Participant's had practical but limited		

knowledge of dietary restrictions (E); (Cardol et al., 2012a)		
Relationship between understanding of diabetes and DSM (E); (Cardol et al., 2012a)		
Opportunities to build self-confidence were limited (E); (Cardol et al., 2012a)	Appropriate resources are required	
More information on diet is needed (U); (Rey-Conde et al., 2005)		
Information provision was limited or not in accessible formats (U); (Hale et al., 2005)		
Finding	Category	Synthesised finding
Staff training was a barrier to DSM (U); (Rey-Conde et al., 2005)	Staff training was limited and this was a barrier to DSM	Limited training and knowledge in staff
Staff skills were mainly in observations and taking blood sugar levels (E); (Rey-Conde et al., 2005)		
Caregivers did not perceive the seriousness of diabetes (U); (Cardol et al., 2012b)		
Diabetes was not a prominent feature in care unless insulin injections required (E); (Cardol et al., 2012b)		
Levels of training were varied: nurses were better qualified and caregivers sought help from doctors (E); (Cardol et al., 2012b)	Staff training was varied and inconsistent	
Key-worker knowledge and understanding: diabetes management varied and limited (U); (Trip et al., 2015)		
Differences between caregivers in level of support for autonomy (E); (Cardol et al., 2012b)		
Key-worker knowledge and understanding: knowledge of impact of comorbidities was		

varied and limited (U); (Trip et al., 2015)		
Frustration over lack of consistency in care (U); (Trip et al., 2015)		
Lifestyle police: caregivers felt personally responsible for the health status of people with ID and focussed on controlling dietary intake (U); (Trip et al., 2015)	Caregiver attitudes may reflect further training needs	
Fear and insecurity in staff over supporting DSM (E); (Rey-Conde et al., 2005)		
Lack of motivation for DSM regarded as dispositional in people with ID (E); (Cardol et al., 2012b)		
Health care professionals are positioned as being competent in a broad sense, holding a higher level of diabetes knowledge (E); (Rouse and Finlay 2016)		
Lack of motivation and preferences are seen as barriers for people with ID (E); (Rey-Conde et al., 2005)		
Dilemmas between enabling autonomy and safeguarding health-care (U); (Trip et al., 2015)	Caregiver dilemmas	
Caregivers were aware of risks versus autonomy (E); (Whitehead et al., 2016)		
Dilemmatic repertoires were presented regarding people with ID's independence (U); (Rouse and Finlay 2016)		

Repertoires of risk management and control presented dilemmas against independence (E); (Rouse and Finlay 2016)		
Responsibility and accountability are constructed as shared and problematic (E); (Rouse and Finlay 2016)		
Dilemmas between enabling autonomy and safeguarding health-care (E); (Cardol et al., 2012a)		
Finding	Category	Synthesised finding
People with ID spoke about practical DSM experiences and abilities (E); (Rey-Conde et al., 2005)	Positive perceptions and statements of DSM abilities and awareness from people with ID	Potential for effective DSM with appropriate support
People with ID proud of skills, though these were limited (E); (Rey-Conde et al., 2005)		
People with intellectual disabilities described themselves as competent in relation to DSM (U); (Rouse and Finlay, 2016)		
Repertoires of confidence in relation to recognising symptoms (U); (Rouse and Finlay, 2016)		
Constructing a positive identity: participants with ID described the needs for support but defended themselves against being seen as incompetent (E); (Rouse and Finlay, 2016)		
People with ID construct themselves as 'lazy' to defend against being seen as disabled (E); (Rouse and Finlay, 2016)		

Lack of competence was often described as due to external factors by people with ID, such as the attitudes of doctors (E); (Rouse and Finlay, 2016)		
Positive comments about exercise from caregivers (U); (Rey-Conde et al., 2005)		
Blood Sugar Levels were not fully understood by people with ID but symptoms of blood sugar changes were recognised (U); (Hale et al., 2005)		
Participants were good at remembering to monitor blood sugar levels but needed support (E); (Hale, 2005)		
DSM is related to self-confidence (E); (Cardol et al., 2012a)		
Concern and conflict in diet but some positive choices (E); (Rey-Conde et al., 2005)		
Participants showed understanding through language related to diabetes (E); (Dysch et al., 2012)		
Participants described the fluctuating state of having diabetes (E); (Dysch et al., 2012)		

Participants described the physical effects of diabetes (U) (Dysch et al., 2012)		
Participants were aware that walking was good for DSM and that have a walking “buddy” would help with this (E) (Hale et al., 2011)		
Participants reported multiple health difficulties (U); (Dysch et al., 2012)		
Daily negotiated autonomy in relation to medication: Participants were almost fully independent with occasional support (E); (Whitehead et al., 2016)	Examples of effective DSM with flexible and creative support from caregivers	
Daily negotiated autonomy in relation to insulin injections: Participants were almost fully independent with occasional support (E); (Whitehead et al., 2016)		
DSM relaxed during special occasions (E); (Cardol et al., 2012a)		
Daily negotiated autonomy in relation to insulin injections: Participants were almost fully independent with occasional support (E); (Whitehead et al., 2016)		
Renegotiation of autonomy in relation to goals: heathier diet (E); (Whitehead et al. (2016)		
Renegotiation of autonomy in relation to goals: living arrangements (E); (Whitehead et al. (2016)		

<p>People with ID were supported to be autonomous during medication adjustments but control was sometimes increased during these times, then readjusted accordingly (E); (Whitehead et al., 2016)</p>		
<p>Families and support staff felt that cognitive limitations were the biggest barrier but tailored education could help (E); (Rey-Conde et al., 2005)</p>		
<p>Prompts, diet management and planning works well (E); (Rey-Conde et al., 2005)</p>		
<p>Nurturing self-management skills: creating opportunities to check understanding and providing education on shopping, cooking and menu planning was limited by time (U); (Whitehead et al., 2016)</p>		
<p>Dietary choices described as negotiated, ongoing and supported (E); (Whitehead et al., 2016)</p>		