

Northumbria Research Link

Citation: Marks, Anne L, Mahoney, Natasha, Chen, Yu-Wei, Cordier, Reinie, Buchanan, Angus and Wilson, Nathan J (2022) Health promotion challenges for young adults living with intellectual disability and type 1 diabetes. *Journal of Intellectual Disabilities*, 26 (4). pp. 853-868. ISSN 1744-6295

Published by: SAGE

URL: <https://doi.org/10.1177/17446295211032767>
<<https://doi.org/10.1177/17446295211032767>>

This version was downloaded from Northumbria Research Link:
<https://nrl.northumbria.ac.uk/id/eprint/49183/>

Northumbria University has developed Northumbria Research Link (NRL) to enable users to access the University's research output. Copyright © and moral rights for items on NRL are retained by the individual author(s) and/or other copyright owners. Single copies of full items can be reproduced, displayed or performed, and given to third parties in any format or medium for personal research or study, educational, or not-for-profit purposes without prior permission or charge, provided the authors, title and full bibliographic details are given, as well as a hyperlink and/or URL to the original metadata page. The content must not be changed in any way. Full items must not be sold commercially in any format or medium without formal permission of the copyright holder. The full policy is available online: <http://nrl.northumbria.ac.uk/policies.html>

This document may differ from the final, published version of the research and has been made available online in accordance with publisher policies. To read and/or cite from the published version of the research, please visit the publisher's website (a subscription may be required.)

TITLE PAGE

Health promotion challenges for young adults living with intellectual disability and type 1 diabetes

Running title: Intellectual disability and type 1 diabetes

Anne L. Marks

School of Nursing and Midwifery, Western Sydney University

Western Sydney University, School of Nursing and Midwifery, Building G10,
Hawkesbury Campus. Locked Bag 1797

Penrith, NSW 2751, Australia.

Email: anne.marks@westernsydney.edu.au

ORCHID: 0000-0001-6210-572X

Natasha Mahoney

School of Nursing and Midwifery, Western Sydney University

School of Occupational Therapy, Social Work and Speech Pathology, Faculty of
Health Sciences, Curtin University

Email: N.Mahoney@westernsydney.edu.au

ORCID: 0000-0002-1794-875X

Yu-Wei Chen

Faculty of Health Sciences, the University of Sydney.

Email: yu-wei.chen@sydney.edu.au

ORCID: 0000-0001-5965-1279

Reinie Cordier

Department of Social Work, Education and Community Wellbeing, Northumbria
University

School of Occupational Therapy, Social Work and Speech Pathology, Faculty of
Health Sciences, Curtin University

Email: reinie.cordier@northumbria.ac.uk

ORCID: 0000-0002-906-5300

Angus Buchanan

School of Occupational Therapy, Social Work, and Speech Pathology, Faculty of Health Sciences, Curtin University

Email: a.buchanan@curtin.edu.au

ORCID: 000-0001-5268-5433

Nathan J. Wilson

School of Nursing and Midwifery, Western Sydney University

Email: N.Wilson@westernsydney.edu.au

ORCID: 0000-0002-6979-2099

Funding statement

This research was funded by a grant from The Endeavour Foundation Endowment Challenge Fund. The funding body has not imposed any restrictions on free access to or publication of the research data.

Acknowledgement statement

We thank the participants who agreed to be a part of this study in addition to Ciarain Hoey and Jena Bednarz who worked as research assistants on the project.

Conflict of interest

The authors declare that there are no conflicts of interest in connection with this article.

Ethics Approval Statement

The Human Research Ethics Committee from Western Sydney University granted ethical approval for this study.

Health promotion challenges for young adults living with intellectual disability and type 1 diabetes

Abstract

Background: Self-management of type 1 diabetes mellitus (T1DM) can be challenging for people with intellectual disability. Often, parents provide health support due to lack of appropriate services outside the home. The study aim was to identify barriers and facilitators to T1DM self-management for young adults with intellectual disability and the implications for health promotion.

Methods: Five male participants with intellectual disability aged 17-26 years and seven parents were interviewed between October 2017 and February 2019. Interview data were descriptively analysed.

Findings: Two categories for barriers and facilitators were identified: 1) Diabetes self-management is complex (carbohydrate counting, blood glucose level monitoring, insulin therapy, technology); 2) support for diabetes care (reliance on parents and carers, the National Disability Insurance Scheme, mainstream diabetes service support).

Conclusions: Parents are critical for the support of people with intellectual disability and T1DM in the absence of disability staff with appropriate health skills.

INTRODUCTION

Currently, there is a lack of accessible and adaptable diabetes self-management programs specifically for people with intellectual disability. This is of particular concern as the prevalence of type 1 diabetes mellitus (T1DM) in conditions associated with intellectual disability (e.g., Down syndrome) is higher than the general population (Hillege et al., 2013; Lämmer, 2008; McVilly et al., 2014; Rey-Conde, 2007). Management of T1DM may also be compromised for people with intellectual disability during the transition to adulthood when the structure and support available within the school system no longer exists. Moreover, the funding of direct health care and support under the Australian National Disability Insurance Scheme (Lind et al., 2017), a new model where the Australian Government provides funding to the individual who decides how the money is expended, rather than the disability service (Collings et al., 2016), remains unclear and is rapidly changing, representing an added policy barrier to supported self-management of chronic illnesses for people with intellectual disability.

T1DM is an endocrine disorder where daily monitoring and management of blood glucose (BGL) and insulin levels are required to avoid an acute health episode, added health problems and, potentially, death (Craig et al., 2011). Optimal diabetes self-management for health promotion includes intensive insulin therapy, requiring either multiple daily injections or insulin pump therapy (Craig et al., 2011). In addition, carbohydrate counting, BGL tests and management of acute complications are essential practices. Diabetes self-management requires active participation from the person with diabetes, including an understanding of diabetes and skills to perform self-care (Taggart et al., 2013). However, total independence is unlikely for many people with intellectual disability, leading to increased dependency

on family members and disability support personnel, many of whom have no health-related training. Continuous support from others may foster dependence, disempowerment, and less opportunity for self-management of diabetes.

As a way of managing these issues, simplified and less-optimal diabetes treatment regimens (e.g., less frequent insulin administration, BGL testing or carbohydrate counting) can be implemented for people with intellectual disability. In a study by Brown et al. (2017) diabetes physicians set alternative BGL targets for people with intellectual disability and often simplified insulin regimens (two injections per day) for safety reasons, to minimise the risk of hypoglycemia and due to the lack of support for frequent insulin administration. Physicians reported feeling conflicted, as they were aware of the potential for long term health complications if BGLs were elevated due to sub-optimal diabetes care. If diabetes is not managed appropriately, poor glucose control may lead to chronic health complications, frequent hospitalisation, longer length of stay, reduced quality of life and increased health costs (Hillege et al., 2013; Lämmer, 2008; McVilly et al., 2014; Rey-Conde, 2007).

The need for supervision of diabetes care and the reluctance of others outside the home to accept responsibility has human rights implications for people with intellectual disability, such as access to employment, social activities and residential accommodation (Cardol et al., 2012). A key predictor of a person's capacity to work is the ability to manage activities of daily living, which can be difficult for young adults with intellectual disability and T1DM entering the workforce. Supported and sheltered employment services in Australia are not funded to provide direct support for health or personal care required for T1DM. This presents the likelihood of the exclusion of young people with intellectual disability and T1DM from social and economic participation, despite having the functional skills to participate in the workforce.

Exploratory research about the self-management of T1DM for young adults with intellectual disability is extremely limited (MacRea et al., 2015). This research gap is disconcerting given the high health and economic burden of poor self-management of diabetes. This research aims to start to fill this gap in our knowledge by talking directly to people with intellectual disability and their families in order to identify the barriers and facilitators to optimal T1DM self-management for young adults with intellectual disability.

METHODS

Research design

This study used a qualitative descriptive method to collect interview and diabetes self-management data directly from participants with intellectual disability and their family caregiver in the home context. Qualitative description is a naturalistic method well suited to health and nursing research that seeks a categorical, non-interpretive analysis that is not conceptual in its approach or outcome (Kim et al., 2017). It was the most appropriate method for this study as we were not seeking an interpretive and thematic understanding, rather a descriptive insight into T1DM self-management.

Participants

The inclusion criteria for the study were young adults aged 17 to 30 years with T1DM and intellectual disability living in Australia. This age range was selected to address the aim of the study; to identify barriers and facilitators to T1DM self-management for young adults with intellectual disability and the implications for health promotion. Participants were purposively recruited through the researchers' existing networks

via email and advertised on Facebook diabetes and intellectual disability support groups, between October 2017 and February 2019. Five males with intellectual disability and T1DM (aged 17-26 years) responded and agreed to participate in the study. Seven of their parents also participated, comprising of three mothers and four fathers (See Table 1). Participants gave written informed consent using a modified participant information statement and consent form; parents also signed the consent form as they participated in and supported their son with intellectual disability within the joint interview. Nil participants withdrew from the study and pseudonyms have been used throughout to maintain anonymity.

<INSERT TABLE 1 ABOUT HERE>

In addition to collecting demographic data, participants were screened using the Inventory for Client Agency and Planning (ICAP) (Bruininks et al., 1986). The ICAP provides an overview of any adaptive (motor, social/communicative, personal living and community living skills) and maladaptive (internalised, asocial, externalised, general) behaviour, and produces a Broad Independence Score. The ICAP also provides a service score reflecting the level of care a participant requires. These scores range from 1 (Total personal care and intense supervision) to 9 (Infrequent or no assistance for daily living). Two participants reported a service score of 3, indicating extensive personal care and/or constant supervision. The remaining participants reported services scores ranging from 5 to 7, indicating regular to limited personal care. Most maladaptive scores were within the *'normal'* to *'marginally serious'* range, with one participant exhibiting general and asocial maladaptive scores in the *'serious'* range. Broad Independence scores ranged from 411 to 484, indicating independence in most domains.

Procedure

Ethical approval for this study was gained from the [REDACTED] Human Research Ethics Committee. Face to face interviews with participants and their parent/s were conducted using open-ended questions and a semi-structured interview guide that was informed by the literature (Jacob and Furgerson, 2012), to stimulate discussion about living with T1DM and intellectual disability. The first and last authors, both skilled nurses and interviewers with expertise in diabetes and intellectual disability respectively, conducted all interviews. Questions covered the person's diabetes history, daily schedule, challenges managing diabetes, factors that supported independence with diabetes management, and the types of supports needed to make self-management possible. Plain language deemed suitable for each individual participant was used during the interview. Parents were also available to clarify or modify questions if required to assist their son to participate in the discussion. Interviews lasted on average 30 minutes, were digitally recorded, transcribed verbatim by a professional transcription service and audited for accuracy by the first author.

Data analysis

Descriptive analysis of the qualitative interview data was conducted by the first and last authors to identify barriers and facilitators and to interpret the underlying meaning of the text (Minichiello et al., 2004) (Table 2). Credibility was ensured through the screening of transcripts, categorisation of data by two separate team members, and the entire research team deciding on the final organisation and presentation of categories. Categories for barriers and facilitators of self-

management of T1DM were developed to present meaningful insight into the daily care needed for optimal self-management of T1DM.

<INSERT TABLE 2 ABOUT HERE>

FINDINGS

Participants discussed several barriers and facilitators for T1DM self-management. The two main categories were: 1) Diabetes self-management is complex (carbohydrate counting, BGL monitoring, insulin therapy, technology); 2) support for diabetes care (reliance on parents and carers, the NDIS, mainstream diabetes service support). It was evident throughout the interviews that parents, their son's main advocates, had much to say about T1DM self-management issues whereas the participants with intellectual disability responded mainly with single word answers to very concrete questions. Hence, the quotes provided in this research are predominately from parents as they provided more detailed responses, however, the young adult was always present and involved in all discussions. Findings represent the experience of the whole family.

Category 1: Diabetes self-management is complex

Carbohydrate counting

All five participants were unable to count carbohydrates independently, which is a significant barrier for diabetes self-management. Ryan was 17 years old, attending high school and used multiple daily insulin injections. His mother reported, "*Diabetes self-management is a bit too complex and stresses him out*". The diabetes dietitian provided written information as one strategy to facilitate carbohydrate counting. The

inability to count carbohydrates prevented Ryan from accessing insulin pump therapy.

Aaron was 23 years old and attended a disability day program. He was also using multiple daily insulin injections. His mother stated:

He just doesn't get the carb thing at all. He thinks he understands what has carbs in it and then the next time he goes to do it he forgets. I can't get my head around it let alone him.

Similarly, to Ryan, this prevented the use of insulin pump therapy, although an additional deterrent was "...not wanting an extra attachment due to tactile issues".

Andrew was 26-years old, recently diagnosed with T1DM and attended a disability day program. He required one insulin injection (long acting Lantus) a day due to a partial remission or 'honeymoon phase' where there are low exogenous insulin requirements. Facilitators for Andrew included support from his mother who counted carbohydrates and packed his food each day or wrote a guide for the food he could eat if he was going out. The disability carers at the day program also assisted with this.

Gavin was 17-years old and attended high school. He used an insulin pump facilitated by parental assistance with carbohydrate counting and the *ControlMyWeight*[™] app on his phone.

Joshua was 21-years old and attended a day program four days a week and had private carers one day a week. He used insulin pump therapy and was totally dependent on others for his diabetes care, including carbohydrate counting. His

mother wrote the amount of carbohydrate on the food that he eats so that carers could enter the amount into his pump.

Blood glucose level monitoring

Another barrier to diabetes self-management was remembering to perform diabetes care and the tendency to become distracted. This was the case for Gavin:

You are constantly reminding - have you done your finger prick? He'll do the finger prick and walk off and I'll say, what was it? I don't know. He didn't even look at the monitor. (Gavin's mother)

Aaron's mother explained the consequences of not performing blood glucose level testing:

If we are away we have to manage him having a hypo from 2000km away and there are no warnings. He was on a day service and he ended up in the gutter half unconscious.

All participants had limited or no ability to interpret blood glucose levels. This was captured by Gavin's parents who stated:

Gavin knows the theory - he can talk the talk he just can't walk the walk. He can tell you exactly what he needs to do, he knows that pump inside out. Which is very confusing for people who don't know him because he sounds like he knows exactly what he is doing and he does in theory, he just can't put it into action. You've constantly got to be at him. (Gavin's parents)

All parents, disability carers or school staff reviewed BGL results and assisted with treatment when required which facilitated self-management. For participants using an insulin pump, they received warning messages and suggestions for treatment when the BGL was out of range.

All participants required assistance with prevention, identification and treatment of hypoglycaemia. Gavin's father deliberately picked workplaces that were within 5min radius of home and reduced Gavin's insulin dose.

We find he needs less insulin at work experience as he is more active, so they have created a second setting in his pump. He turns it on before he starts and he's less likely to have a hypo. We give them his emergency plan if they want it.

Insulin therapy

All participants either required supervision of insulin doses or were totally dependent on others to administer insulin; a significant barrier for self-management. Ryan and Aaron administered their own insulin injections with parental, school staff or disability carer supervision. Aaron explained, *"I try and be independent with most of it, if I need help then I can ask someone."* His mother reported, *"They have to sign the book to make sure they have visually seen him inject himself because he will tell them he has done it and unless they see it there is no way of knowing"*.

Gavin's parents explained how they facilitate insulin delivery:

We gave instructions for the pump to carers in case they want to follow along to make sure he is doing it right. We try to make things simple so that there are no qualms about taking him.

Joshua required someone to enter his information into the pump for his insulin dose.

His father explained how this was a significant barrier:

It is hard to get services to take on new things. The established services have strict protocols and they are very aware of taking on liability. We find they get

anxious when it comes to a machine (pump) even though for us it is quite simple and straightforward. We are aware that it is outside normal bounds and we accept the risk, otherwise Joshua doesn't get the services.

All participants were unable to independently adjust insulin doses. Aaron used a smart glucose meter to facilitate calculation of insulin doses. “*The diabetes service put in the settings and then the meter says how much insulin to give so I don't have to work it out*”. Other facilitators were a written sliding scale of doses depending on the glucose level (Ryan), and an insulin pump that calculates the dose based on the glucose level and carbohydrate amount (Gavin and Joshua).

Technology

Gavin and Joshua's parents found the use of insulin pump therapy very beneficial for self-management. Gavin's father stated:

The pump has made our life easier because everything is pre-set, I can do a download on the pump and I can see his entries. We went back to injections briefly - it was actually more dangerous because he was injecting himself every time he wanted to eat something, he was stacking the insulin and we had no record.

Joshua's father also explained the benefits:

The pump it is very straight forward, if we give the information the pump does the calculation so as long as the carbs are right and the BGL is right, in my opinion, it is very low risk. This allows for him to enjoy life more fully - if he is a bit high we adjust it through the pump. It is on-going management instead of hoping that things will stay even during the day.

However, inserting the subcutaneous infusion set for the insulin pump was a major barrier for Gavin and Joshua who were unable to perform this independently.

Parents usually had the full responsibility of inserting the insulin pump set every three days. Joshua's father discussed the difficulties:

We are the only ones who can change the pump set. I think my expectations are that we should be able to find a service that do the set change but we haven't yet. Once I was called out three times in a week.

The high cost of continuous glucose monitoring (CGM) prevented access to this technology for some participants. CGM assists with the identification and prevention of hypoglycaemia and hyperglycaemia to improve blood glucose control. Gavin's father received alerts on his phone from the CGMS when the BGL was out of range. He would then follow up with Gavin. He explained:

I'm on the phone straight to him if it's high. He uses a CGM and my phone also alarms. We make the workplace aware that he has diabetes and that he has to carry his phone, and he will be receiving messages throughout the day to prompt him to give extra insulin or treat a low BGL.

Category 2: Support for diabetes care

Reliance on parents and carers outside the home

All parents expressed the amount of assistance their child required for diabetes care. Although this was often a barrier, many parents ceased or adapted their employment to be readily available to facilitate diabetes care. Gavin's mother explained, "After Gavin was diagnosed Adam took a redundancy. When Gavin is on work experience Dad is on call 24/7".

Another barrier was accessing disability carers who were trained and willing to assist with diabetes care. Two parents described their difficulties. Aaron's mother said,

"They don't have the insight, they have no idea about the depth of it".

Joshua's father had varied experiences:

The disability system makes a clear distinction between health and disability and they reluctantly accept that Joshua can't get services unless his diabetes is managed. Disability services especially under the new scheme, have a high casual workforce, so there is a lot of turnover. We have had an issue getting new services because of lack of training, and that has made us less able to move between services. One day a week he had a carer one on one who had insulin pump training and the other four days were at the day programme and the service took it upon themselves to get training for the staff. They were happy to do the pump and the finger prick testing.

The National Disability Insurance Scheme

The introduction of the National Disability Insurance Scheme (Lind et al., 2017) enabled access to carers outside the home (facilitator), however some parents expressed their frustration with the new system (barrier). Gavin's mother was very overwhelmed, explaining:

I'm about to take two months off work, The NDIS has just about done my head in - I spend my 45min train journey sending emails. We had a review because Gavin didn't have respite in his plan initially.

Joshua's father found that:

Disability services have become a little bit greedy and they will charge us the maximum. We have been in the disability system for three years and we are only just starting to get somewhere with a huge amount of effort on a number of people's part and it is so time consuming. I get up at 4am just to keep things going and every day I'm chasing service providers. I do that because I have a reason to do it and I won't give up, but it's hard.

Ryan's mother spoke positively about the NDIS:

He has just recently been accepted onto the NDIS so that is going to make it a lot easier for him to access community support without me. There are two disability workers we have identified so far that have diabetes too, so they are great.

Aaron's mother explained the difference it made to her son:

He now has a life instead of sitting in front of the Xbox all day every day at home, not eating, not injecting, not pricking his finger. So, for us the NDIS has been incredibly great.

Mainstream diabetes service support

Joshua's father discussed difficulties accessing diabetes specialist support experienced with intellectual disability, particularly for training disability services:

We sense reluctance from the diabetes service to provide the training probably because of their lack of resources. They treated him as though he was an adult and he is still in the same category as a child you know, and we have to look after him as parents and so we felt a little bit unsupported.

DISCUSSION

This study identified a number of barriers for T1DM self-management, including difficulties with insulin administration, BGL monitoring and carbohydrate counting. Additional barriers included reduced access to insulin pump therapy and CGM, reliance on parents and carers outside the home, the complexity of accessing direct health support within the NDIS, and lack of intellectual disability-specific diabetes service support. Of note is that none of the young adults who had left school were in any type of employment, rather their support under the NDIS were either a day program model or 1:1 support to access the community where their T1DM could be more easily managed. Facilitators included parental support for diabetes care, written guidelines, continuous glucose monitoring, insulin pump therapy, funding for carers outside the home and diabetes training.

Support for diabetes care

The complexity of diabetes care was often overwhelming for the parents and young adults in the current study and constant support from family or external carers was required. Family carers are noted to be the major contributors to the daily care and support of people with intellectual disability and chronic illness (Brown et al., 2017; Hillege et al., 2013; NSW Ministry of Health, 2012; Rey-Conde, 2007). Parents in this study described the high level of dependence on them as carers where they made a number of sacrifices such as resigning from work. Parents in the study spent hours finding disability services, planning for care outside the home, worrying about diabetes emergencies and planning their day around their child's activities in order to be readily available. If funded disability support had a built-in component that enabled ongoing health-specific care outside the home for people with intellectual disability and chronic illnesses, it would not only have the potential to benefit the

person with intellectual disability, but also their family caregivers. Previous research has found that providing better access to professional support for parents of children with intellectual disability is important to long-term parental well-being (White, 2004). Another option that has been operating in the UK for some years, is joint service commissioning by health and social services as a means to ensure that the person with intellectual disability has funding and receives appropriate health support in their daily lives (Hudson, 2011).

Complexity of the National Disability Insurance Scheme

Overall, the NDIS was considered more of a barrier than a facilitator for diabetes self-management. This added complexity has been noted by others, for example Collings et al. (2016) identified the need for additional advocacy and support planning for people with intellectual disability and complex health conditions. Approximately one third of parents of children with intellectual disability have previously reported difficulty accessing funding and found it difficult to communicate with the NDIS (Ranasinghe et al., 2016). The common issues parents reported were complicated application forms and processes, a lack of workers and a point of contact that is familiar with their child, and lack of consideration of ongoing funding for children with permanent disability. Parents in the current study spent a considerable amount of time searching for appropriate services that could cater for both intellectual disability and T1DM. Choices were often limited and opportunities for social and economic participation, such as employment, were often not available due to lack of support for T1DM care. Rather, disability day programs or work experience close to home were utilised due to the need for parental support, resulting in further reduced social and economic participation for the parents

themselves. No one talked about a future vision where the person with intellectual disability and T1DM could be employed while having access to appropriate health support when needed, instead there appeared to be an acceptance that this was not a feasible option.

In addition to access barriers with the NDIS, the disability workforce is not as skilled with T1DM management and support as is perhaps required (Cardol et al., 2012; Taggart et al., 2013; Trip et al., 2015). Education for support workers who work with people with intellectual disability and T1DM is critical in order to promote self-management, reduce health inequalities and lower the burden on families (Trip et al., 2015). The high turnover of staff in the disability sector also presents challenges for maintaining a workforce experienced in diabetes care (Brown et al., 2017; Reichard and Stolzle, 2011). In addition, it has also been reported that disability services are apprehensive and reluctant to perform diabetes care (Rey-Conde, 2007), particularly insulin administration, as was discussed by parents in this study. Although the NDIS does have a category to fund medical-condition specific training for disability support workers (National Disability Insurance Agency, 2019) there was no evidence of these types of training within the data and there are no identified studies in the literature reporting on use and outcomes from such training. Further, training a reluctant workforce in health specific procedures seems a compromise to employing staff with the appropriate skills and professional background, such as specialist intellectual disability nurses (Wilson et al., 2019), to not only attend to the health procedures, but also act appropriately when things invariably go wrong.

Mainstream diabetes service support

International studies have identified that national standards for diabetes

management are only partially achieved for people with intellectual disability (Shireman et al., 2010; Taggart et al., 2013). The needs of people with intellectual disability, in particular for adults, are often not effectively met by the mainstream Australian health service system either (NSW Ministry of Health, 2012) and these barriers were noted in this study. Some of the reported difficulties faced by mainstream health staff include struggling to communicate with people with intellectual disability, not understanding the role of caregivers, and generally feeling under-prepared in how to best work with people with intellectual disability (Lewis et al., 2017). Joshua's father expressed the lack of appropriate diabetes support once his son moved from paediatric to adult care. He was treated as an independent adult despite his level of cognitive functioning and dependence on his parents. Most outpatient diabetes service clinics do not cater for the additional time for diabetes education and support that is required for people with intellectual disability (Brown et al., 2017). Longer appointment times, more frequent review of diabetes care and continuity of staff would be beneficial to more fully meet the needs of the person with intellectual disability (Brown et al., 2017). Further strategies include shared clinics with practitioners from both diabetes and intellectual disability services, intellectual disability liaison nurses and training for diabetes practitioners about communication and using adapted resources. None of these strategies or services are reported in the Australian literature reflecting the barriers faced by people with intellectual disability and their parents as reported in this study.

Insulin pump therapy

Participants in the current study who were prescribed intensive insulin therapy either had multiple (4) daily injections or insulin pump therapy. Diabetes research has

demonstrated a statistically significant reduction in Hemoglobin A1c (a measure of glucose control) in people using insulin pump therapy compared to multiple daily injections (Craig et al., 2011). According to the Australian national evidence-based clinical care guidelines for T1DM, insulin pump therapy also reduces hypoglycaemia and microvascular complications (Craig et al., 2011). Diabetes services often use these guidelines for insulin pump therapy which include: the ability to perform carbohydrate counting, testing BGLs four or more times per day, reliable adult supervision (in paediatrics), a history of good self-management and the ability to master technical skills. Therefore, people with intellectual disability are often considered unsuitable for insulin pump therapy and are excluded from the physical and emotional health benefits, such as better quality of life and treatment satisfaction. In the current study, Gavin and Joshua's parents expressed these same quality of life benefits for their child with intellectual disability, both of whom had an insulin pump.

Of note, however, was that according to their ICAP scores Gavin and Joshua required extensive personal care and/or constant supervision provided by parents, school or disability support workers. Although the other participants, for example, had higher ICAP scores indicating a greater level of independence, the major barrier to them accessing insulin pump therapy was their inability to count carbohydrates and reluctance from the diabetes team to prescribe this therapy. In this case it appears that the greater the support needs of the person with intellectual disability and therefore the greater amount of support provided, equated to more optimal T1DM management. Gavin and Joshua are examples of how insulin pump therapy can be successfully used for people with intellectual disability. In addition to long-term health benefits, parents reported improved safety due to pump features such as

alerts, insulin dose calculations, prevention of insulin overdosing, and a downloadable record of BGLs, carbohydrates and insulin doses. Yet, both the Australian T1DM guidelines and the NDIS funding frameworks seem to be collectively inadequate at matching the needs of all people with intellectual disability and T1DM, regardless of their level of intellectual disability, with the appropriate funded supports that do not hinder full social and economic participation.

Continuous glucose monitoring

Maintaining near normal BGLs reduces microvascular and macrovascular complications but may increase the risk of hypoglycaemia (Danne et al., 2017). As illustrated in this study, people with intellectual disability often experience difficulties with preventing, recognising and treating hypoglycaemia. As previously discussed, physicians often preferred BGLs to be higher than the typical targets for people without intellectual disability, due to safety concerns. Continuous glucose monitoring (CGM) has been shown to reduce HbA1c without increasing hypoglycaemia (Danne et al., 2017). CGM should be considered in all people with T1DM who are not achieving glucose targets or are experiencing problematic hypoglycemia (Danne et al., 2017). CGM systems are available for people using MDI or insulin pumps (van Beers et al., 2016) and consist of a small adhesive patch with sensors that send constant BGL reports to either a mobile device or insulin pump. In addition to the metabolic benefits of CGM, studies have reported a significant improvement in subjective well-being and treatment satisfaction possibly due to HbA1C improvement and the reduction of hypoglycemia (Lind et al., 2017).

CGM was only used by Gavin in the current study and it worked well as his parents received alerts on their phone when the BGL was out of range and were

able to provide support remotely to him while at school via his phone. A noted barrier to using CGM for other participants was the financial cost of the sensor and transmitter. Until recently, the Australian Government only provided funding for fully subsidised CGM for people under 21 years of age who met certain criteria (Diabetes Australia, 2015). The Government has now added funding for people over the age of 21 years which removes this noted barrier and represents a major tool to help increase independence and decrease the worry of parents. A person with intellectual disability is likely to meet the criteria such as; the inability to recognise, or communicate about, symptoms of hypoglycaemia; significant fear of hypoglycaemia for the child/young person or a family member/carer, which is seriously affecting the health and wellbeing of the child or young person or contributing to hyperglycaemia as a reaction to this fear or at least one episode of severe hypoglycaemia within the last 12 months (Diabetes Australia, 2015).

CONCLUSION AND IMPLICATIONS FOR PRACTICE

This study has highlighted the significant reliance that these young adults with intellectual disability have on their parents to manage their T1DM to enable optimal health. Major barriers to diabetes care and a more independent life; include the complexity of the NDIS and the inability for mainstream services to meet the unique needs of people with intellectual disability. An inability to count carbohydrates, and thus adequately use an insulin pump, is an area that requires future research and strategies to solve. At this point in time, very few disability services actually employ health trained staff such as nurses and given the NDIS currently offers funding for external training of support workers with medical needs, it is likely such staff are unaffordable. These young adult males with intellectual disability were restricted to

accessing localised day programs and/or 1:1 community support suggesting that employment, whether supported or sheltered, has been ruled out even though their level of function indicates it would be achievable. That is, the choices of support are being dictated by the chronic illness rather than what was possible for the person with intellectual disability. Disability services should consider employing staff, such as specialist nurses, who have the skills to care for and attend to any type and degree of chronicity so that having a chronic illness is not the driver of support that currently appears the case. In addition, specialist nurses would fulfil a vital role in health promotion for this vulnerable population.

Strengths and Limitations

This exploratory study adds to the limited research on self-management of T1DM for young adults with intellectual disability. Data were collected from a small group of male participants and their parents living in two Australian states. Self-management of both insulin injections and insulin pump therapy was explored. Due to the lack of female participants and the sample size and methods used, the findings may not represent the experiences of all young adults with intellectual disability and T1DM. In addition, the Australian context in which this research was conducted may impact generalisability to other populations, especially in relation to insurance schemes.

References

- Brown M, Taggart L, Karatzias T, et al. (2017) Improving diabetes care for people with intellectual disabilities: a qualitative study exploring the perceptions and experiences of professionals in diabetes and intellectual disability services. *Journal of Intellectual Disability Research* 61(5): 435-449.
- Bruininks RH, Hill, B. K., Weatherman, R. F., & Woodcock, R. W (1986) *Inventory for Client Agency and Planning*. Chicago: Riverside Publishing.
- Cardol M, Rijken, M. & van Schrojenstein Lantman-de Valk, H (2012) Attitudes and dilemmas of caregivers supporting people with intellectual disabilities who have diabetes. *Patient Education and Counseling* 87(3): 383-388.
- Collings S, Dew, A. & Dowse, L (2016) Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme. *Journal of Intellectual & Developmental Disability* 41: 272-276.
- Craig M, Twigg S, Donaghue K, et al. (2011) National evidence-based clinical care guidelines for type 1 diabetes in children, adolescents and adults. *Canberra: Australian Government Department of Health and Ageing*.
- Danne T, Nimri R, Battelino T, et al. (2017) International consensus on use of continuous glucose monitoring. *Diabetes Care* 40(12): 1631-1640.
- Diabetes Australia (2015) *Continuous Glucose Monitoring*. Available at: <https://www.ndss.com.au/cgm> (accessed 10 November 2019).
- Hillege S, Gallagher, S. & Evans, J (2013) The challenges for families managing an adolescent with an intellectual disability and type 1 diabetes. *Australian Journal of Advanced Nursing* 30(3): 26-32.
- Hudson B (2011) Ten years of jointly commissioning health and social care in England. *International Journal of Integrated Care* 11: e005.
- Jacob SA, & Furgerson, S. P (2012) The qualitative report writing interview protocols and conducting interviews: Tips for students new to the field of qualitative research. *The Qualitative Report* 17(42): 1-10.
- Kim H, Sefcik, J.S. & Bradway, C (2017) Characteristics of qualitative descriptive studies: A systematic review. *Research in nursing and health* 40(1): 23-42.

- Lämmer CW, E (2008) Early onset of type I diabetes mellitus, Hashimoto's thyroiditis and celiac disease in a 7-yr-old boy with Down's syndrome. *Pediatric diabetes* 9(4): 423-425.
- Lewis P, Gaffney, R. J. & Wilson, N. J (2017) A narrative review of acute care nurses' experiences nursing patients with intellectual disability: Underprepared, communication barriers and ambiguity about the role of caregivers. *Journal of Clinical Nursing* 26(11-12): 1473-1484.
- Lind M, Polonsky W, Hirsch IB, et al. (2017) Continuous glucose monitoring vs conventional therapy for glycemic control in adults with type 1 diabetes treated with multiple daily insulin injections: the GOLD randomized clinical trial. *Jama* 317(4): 379-387.
- MacRea S, Brown, M., Karatzias, T., Taggart, L., Truesdale-Kennedy, M., Walley, R., Sierka, A., Northway, R., Carey, M. & Davie, M (2015) Diabetes in people with intellectual disabilities: A systematic review of the literature. *Research in Developmental Disabilities* 47: 352-374.
- McVilly K, J. McGillivray, A. Curtis, J. Lehmann, L. Morrish, & Speight, J (2014) Diabetes in people with an intellectual disability: a systematic review of prevalence, incidence and impact. *Diabetic Medicine* 31(8): 897-904.
- Minichiello V, Sullivan G, Greenwood K, et al. (2004) *Research methods for nursing and health science*. Sydney: Prentice Hall Health.
- National Disability Insurance Agency (2019) *NDIS Available at: <https://www.ndis.gov.au> (accessed 11 November 2019)*.
- NSW Ministry of Health (2012) Service Framework to Improve the Health Care of People with Intellectual Disability. Available at: <https://www.health.nsw.gov.au/disability/Pages/health-care-of-people-with-ID.aspx> (accessed 10 January 2020).
- Ranasinghe T, Jeyaseelan, D., White, D., & Russo, R (2016) Parent's experiences in registering and accessing funding under the National Disability Insurance Scheme for early intervention services for children with developmental disabilities. *Journal of Paediatrics and Child Health* 53(1): 26-32.
- Reichard A, & Stolze, H (2011) Diabetes among adults with cognitive limitations compared to individuals with no cognitive disabilities. *Intellectual and developmental disabilities* 49(3): 141-154.

- Rey-Conde TFL, N. G (2007) Delivering diabetes care to people with intellectual disability. *Diabetes Voice* 52(2): 16-18.
- Shireman T. RA, Nazir N., Backes J., Pharm D. & Griener A (2010) Quality of diabetes care for adults with developmental disabilities. *Disability and Health Journal* 3(3): 179-185.
- Taggart L, Coates, V. & Truesdale-Kennedy, M (2013) Management and quality indicators of diabetes mellitus in people with intellectual disabilities. *Journal of Intellectual Disability Research* 57(12): 1152-1163.
- Trip H. CJ, Hales L. & Whitehead L (2015) The role of key workers in supporting people with intellectual disability in the self-management of their diabetes: a qualitative New Zealand study. *Health and Social Care in the Community* 24 (6): 789-798.
- Van Beers CA, DeVries JH, Kleijer SJ, et al. (2016) Continuous glucose monitoring for patients with type 1 diabetes and impaired awareness of hypoglycaemia (IN CONTROL): a randomised, open-label, crossover trial. *The lancet Diabetes & endocrinology* 4(11): 893-902.
- White NH, R. P (2004) Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 17(3): 181-190.
- Wilson NJ, Wiese, M., Lewis, P., Jaques, H, & O'Reilly, K (2019) Nurses working in intellectual disability-specific settings talk about the uniqueness of their role: A qualitative study. *Journal of Advanced Nursing* 75(4): 812-822.

Table 1: Demographic data

Participant	Age	Australian state of residence	Vocational Activity	Insulin regime	BGL testing	ICAP Broad Independence	ICAP General Maladaptive	ICAP Service score	Descript of level of care needed	ICAP Notes
Ryan	17	Queensland	School	MDI †	Libre sensor meter, Flash glucose monitor.	467	-8	6	Regular personal care and/or close supervision.	Asocial maladaptive index in 'marginally serious' range.
Aaron	23	Queensland	Day program	MDI	Libre sensor meter, Flash glucose monitor.	484	-2	7	Limited personal care and/or regular supervision.	All scores in normal range.
Gavin	17	Queensland	School	Insulin Pump	Continuous glucose monitor and Finger prick.	472	-33	3	Extensive personal care and/or constant supervision.	Asocial and General maladaptive in 'serious range', others in moderately or marginally serious range.
Joshua	21	New South Wales	Day program	Insulin Pump	Finger prick – standard meter.	411	-7	3	Extensive personal care and/or constant supervision.	All in normal range.
Andrew	26	New South Wales	Day Program	1 injection Newly diagnosed in honeymoon phase.	Finger prick – standard meter.	459	-19	5	Regular personal care and/or close supervision.	Internalised in normal range, Asocial, externalised and general in marginally serious range.

† MDI = multiple daily injections

Table 2. Data analysis process

Data collection	Participants (young adult with ID and diabetes and their parent/s) were interviewed and digitally recorded. Recordings were transcribed verbatim by a professional transcription service to a Word document. Transcripts were checked for accuracy by the first author by comparing them to the recorded interview.																						
Data review	Individual transcripts and audio recordings were reviewed a number of times by the first and last authors.																						
Relevant text selected	Data from individual participant interview transcripts were analysed by the first and last authors independently, looking for information relevant to the study aim - What are the barriers for T1DM self-management? What facilitates T1DM self-management? Facilitators and barriers were highlighted in the Word document and irrelevant information was removed.																						
Barriers and facilitators identified	<p>Common responses across participants were identified.</p> <table border="1"> <thead> <tr> <th>Barriers for T1DM self-management</th> <th>Facilitators for T1DM self-management</th> </tr> </thead> <tbody> <tr> <td>1. Carbohydrate counting</td> <td>1. Parental or external carer support for diabetes care</td> </tr> <tr> <td>2. Remembering diabetes care</td> <td>2. Written guidelines</td> </tr> <tr> <td>3. Interpreting blood glucose levels</td> <td>3. Smart glucose meter</td> </tr> <tr> <td>4. Adjusting insulin doses</td> <td>4. Continuous glucose monitoring</td> </tr> <tr> <td>5. Administering insulin</td> <td>5. Insulin pump therapy</td> </tr> <tr> <td>6. Unable to access insulin pump therapy</td> <td>6. Funding for carers outside the home</td> </tr> <tr> <td>7. Inserting insulin pump infusion set</td> <td>7. Diabetes training</td> </tr> <tr> <td>8. Hypoglycaemia – prevention, identification, treatment</td> <td></td> </tr> <tr> <td>9. Access to continuous glucose monitoring (CGMS)</td> <td></td> </tr> <tr> <td>10. Reliance on parents</td> <td></td> </tr> </tbody> </table>	Barriers for T1DM self-management	Facilitators for T1DM self-management	1. Carbohydrate counting	1. Parental or external carer support for diabetes care	2. Remembering diabetes care	2. Written guidelines	3. Interpreting blood glucose levels	3. Smart glucose meter	4. Adjusting insulin doses	4. Continuous glucose monitoring	5. Administering insulin	5. Insulin pump therapy	6. Unable to access insulin pump therapy	6. Funding for carers outside the home	7. Inserting insulin pump infusion set	7. Diabetes training	8. Hypoglycaemia – prevention, identification, treatment		9. Access to continuous glucose monitoring (CGMS)		10. Reliance on parents	
Barriers for T1DM self-management	Facilitators for T1DM self-management																						
1. Carbohydrate counting	1. Parental or external carer support for diabetes care																						
2. Remembering diabetes care	2. Written guidelines																						
3. Interpreting blood glucose levels	3. Smart glucose meter																						
4. Adjusting insulin doses	4. Continuous glucose monitoring																						
5. Administering insulin	5. Insulin pump therapy																						
6. Unable to access insulin pump therapy	6. Funding for carers outside the home																						
7. Inserting insulin pump infusion set	7. Diabetes training																						
8. Hypoglycaemia – prevention, identification, treatment																							
9. Access to continuous glucose monitoring (CGMS)																							
10. Reliance on parents																							

	<ul style="list-style-type: none"> 11. The National Disability Services Scheme (Lind et al.) framework and processes 12. Reliance on carers outside the home for diabetes care 13. Diabetes services inexperienced with intellectual disability
Categories developed	<p>Data from each participant interview transcript were reorganized into barriers and facilitators. These were discussed with the whole research team. Categories were developed by the first and last authors by clustering similar barriers and facilitators. The entire research team decided on the final organisation and presentation of categories.</p>
Categories finalised	<p>Two broad categories were identified:</p> <ul style="list-style-type: none"> 1) Diabetes self-management is complex (carbohydrate counting, BGL monitoring, insulin therapy, technology) 2) Support for diabetes care (reliance on parents and carers, the NDIS, mainstream diabetes service support).