



Article

The Financial Costs of Registered Nurse-Led Relationship-Centred Care: A Single-Case Australian Feasibility Study

Nathan J. Wilson , Rebecca Reeve , Zhen Lin and Peter Lewis

School of Nursing and Midwifery, Hawkesbury Campus, Western Sydney University, Locked Bag 3, Richmond, NSW 2753, Australia; R.Reeve@westernsydney.edu.au (R.R.); z.lin@westernsydney.edu.au (Z.L.); p.lewis@westernsydney.edu.au (P.L.)

* Correspondence: n.wilson@westernsydney.edu.au

Abstract: People with intellectual disability are accommodated and cared for in a variety of settings in Australia. Direct care is delivered by a mixture of qualified health professionals (nurses) and unlicensed disability support workers in varying combinations depending on the complexity and chronicity of comorbidities experienced by people with intellectual disability. Although some of these disability services continue to employ registered nurses, the size and specialised education of this workforce is decreasing due to a myriad of policy changes, which has the effect of compromising continuity of care and adverse effects on health outcomes. The objective of this study was to compare the differences on the financial cost of a single case using different models of care with, and without, specialised registered nursing input. The single case had profound intellectual disability and multiple chronic and complex health problems and was cared for by a model that included 24 h registered nurse care and support. Four financial scenarios are presented, and the differences both in terms of actual cost, and potential health outcomes are discussed. This study has set the scene for a large study where health economic data can be compared against multiple cases, across a range of care contexts, in order to advance evidence about which models provide the better health outcomes for people with intellectual disability and associated multiple chronic and complex health problems.

Keywords: profound and multiple intellectual disability; health economics; chronicity; nursing; dysphagia



Citation: Wilson, N.J.; Reeve, R.; Lin, Z.; Lewis, P. The Financial Costs of Registered Nurse-Led Relationship-Centred Care: A Single-Case Australian Feasibility Study.

Disabilities **2021**, *1*, 331–346.

<https://doi.org/10.3390/disabilities1040023>

Academic Editor: Roy McConkey

Received: 14 July 2021

Accepted: 23 September 2021

Published: 29 September 2021

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1. Background

People with intellectual disability experience more health problems and die at a younger age on average than people without intellectual disability [1,2]. At most risk are those with more severe to profound disabilities, and disability-related chronic and complex health problems such as dysphagia where the risk of respiratory infections and choking are significantly greater [3,4]; this situation applies worldwide regardless of context. In addition to these clearly defined health disparities, people with intellectual disability also have significantly higher rates of preventable deaths compared to the general population [5]. A recent government report from Victoria, Australia, reviewing the deaths of people living in disability services highlighted that the poor management of health conditions and managing deteriorating health within disability services were among the core reasons that contributed to the death of residents [6]. With respect to the recent COVID-19 virus that has spread globally, people with intellectual disability are reported to have up to a 2.2 times greater fatality rate when compared to the general population [7]. In addition, the social and other restrictions have had an added impact upon people with intellectual disability where specialised nursing support—support that is often not available within a generalised health system—has made a difference to enabling access and better outcomes from health services [8].

These issues continue despite years of peer reviewed literature that has described the problem and summarised the risks, and the production of countless government reports, reviews and restructures that have aimed to ameliorate the adverse effects of these problems. Yet, after the inception of the Australian National Disability Insurance Scheme (NDIS) the disability workforce in Australia is still offered low wages, has high proportions of disability support workers (DSWs) who are under-skilled, has about a 30% casualization rate in the workforce, and has low levels of organisational support for staff training and skill development [9], all of which contribute to adverse health outcomes for people with intellectual disability. Assuming that a quality workforce does in fact lead to quality outcomes, then the picture appears to be quite bleak. We argue that there is at least one quality alternative to the current models of care delivery, in particular for people with intellectual disability and multiple chronic and complex health problems, and this is a registered nurse-led model of relationship centred care [10], that is not only highly technical, but also uniquely relational in its approach [11]. However, this alternative remains one that while still in practice across some contexts [12], has never been compared to a model of care absent registered nurses (RNs) in terms of financial cost.

A critical policy and practice juncture is playing out at this moment that makes a financial analysis timely and important. In policy terms it has been argued that the framework of the NDIS is based on dedifferentiation of disability, where, having intellectual disability is de-emphasised by membership to a universal group of 'people with a disability' [13], (p. 309). This policy not only further marginalises and disadvantages people with intellectual disability, but also overlooks the reality that many people with severe to profound intellectual disability and multiple chronic and complex health problems, require specialised systems and highly paid staff with clinical expertise [14]. To compound these issues, at present, the NDIS is pursuing a delegated model of nursing care where RNs are to be funded to train DSWs how to do many traditional nursing tasks in the absence of direct oversight by RNs [15]. Notwithstanding the lack of empirical evidence for such a model [16], the practice outcome of this model is to reduce the level of skill of the workforce caring for people with intellectual disability by underfunding many disability services that have continued to provide RN-led models of care [17,18]. That is, the situation for people with intellectual disability in terms of overall health outcomes is deteriorating and such policy and practice changes have the potential to make this situation even worse [19,20]. People with intellectual disability are accommodated and cared for in a variety of settings in Australia. Direct care is delivered by a mixture of qualified health professionals (nurses) and unlicensed DSWs in varying combinations depending on the complexity and chronicity of comorbidities experienced by people with intellectual disability [21]. Although some of these disability services continue to employ RNs, the size and specialised education of this workforce is decreasing due to a myriad of policy changes, which has the effect of compromising continuity of care and adverse effects on health outcomes [22].

2. Aim

The financial cost to the health care system(s) of delivering tertiary health care to people with intellectual disability has been calculated. However, the difference made to the cost and benefits of providing health care to individuals depending on whether or not their primary care is planned, coordinated, and delivered by RNs has not been calculated. The aim of this study, therefore, was to compare the cost and benefits of providing health care services to an individual with intellectual disability and multiple, complex comorbidities when:

1. The oversight of day-to-day care is provided by RNs in the person's place of residence.
2. Care is provided by unlicensed DSWs in the absence of RNs.

3. Methods

This single case study and comparison design used a combination of approaches to data collection: for 'the case' we used a 12-month retrospective case file audit and a series of in-house non-participant observations, and then calculated a range of financial costs using

publicly available health economic data; for ‘the comparison’, in the absence of a valid and reliable ‘comparison case’ within our research partner’s accommodation service, we used a collection of related health-support research literature of the topic specific to adults with intellectual disability similar to ‘the case’ and the life context of ‘the case’. Where specific data were not available in the literature, we made assumptions based on available evidence and non-participant observations of ‘the case’ in critical situations where the clinical experience of staff, and hence quality of care and associated outcomes, would have differed in the absence of an RN.

A single case study design is of particular relevance when the researcher is interested in exploring the unique experiences of individuals in order to understand them better, and one of their great strengths is their relatability as opposed to generalisability [23]. Further, in order to truly appreciate and better understand the individual and unique health experiences of a research participant with severe to profound intellectual disability, observational approaches that can support, or contradict, proxy data as well as offer data triangulation, are methodologically critical [24]. That is, there are particular limitations to using case file audits as the reliance on progress to build a full picture should be balanced with the acknowledgement that they are edited version of events produced to create a legal record, and not to provide a narrative. The single case study presented here is context-specific to a 24 h staffed group home for five adults with intellectual disability and associated multiple chronic and complex health problems. The service offered 24 h accommodation for these five adults with one RN staffed for the entire 24 h period, and a number of DSWs who worked under the direction of the RN. We refer to this model of care as registered nurse-led, relationship centred care [10].

3.1. Ethics and Consent

The Human Research Ethics Committee (HREC) at Western Sydney University approved the study (ID: H13526). As it was anticipated that ‘the case’ would be unlikely to be able to provide informed self-consent due to the severity of their intellectual disability, and so a proxy consent process was used. Written proxy consent was provided by the sibling who was the person responsible for ‘the case’. No adverse events were reported and no participants withdrew consent.

3.2. Recruitment

As ‘the case’ was to be drawn from the accommodation services of the research partner, an arms-length purposive sampling approach was used for recruitment. A previously published collective case file audit, based upon 41 participants with intellectual disability and associated multiple chronic and complex health problems [25], was used to inform the characteristics of ‘the case’. The following average characteristics from the collective case file audit were given to the research partner as the ideal inclusion criteria: male, a mean age of 54.2 years, a secondary disability, having limited living and self-care skills, a mean number of chronic illnesses of 4.2, being prescribed four, or more, medications [25] and living in a group home with 24 h staffed RN care and support. Once ‘the case’, hereafter referred to as Derek (not his real name), had been identified by the research partner, RNs working at the group home were approached by email and phone by the RN unit manager of the group home cluster where Derek lived who inquired about the RNs’ interest in participating in the observational part of the research. The group home manager then provided the researchers with a list of names of RNs who were willing to participate—that is, have their practice observed—in the non-participant observational component of the study.

3.3. Procedure

Retrospective file audit. This was conducted at the residential group home where Derek lived during four separate visits by members of the research team (NW and PL at first visit, ZL at second and third visits, and NW at fourth visit). All medical, health

support plans, charts, and daily notes for Derek, dating from July 2019 to June 2020, were provided for perusal in a secure office separate to the main living area where all of the clients spent a large part of their time when awake. A health support needs template was designed to capture various aspects of Derek's care that was provided by RNs. First, it captured Derek's diagnoses and health support needs, the quantity of direct RN support needed (in hours) across each of the seven days of the week as well as for the range of specialised health appointments (e.g., endocrinologist) and medical reviews (e.g., annual health check) each year that necessitated RN input. It was also used to record each of the health support plans (e.g., seizure management plan) that were developed and reviewed by Derek's primary RN.

Non-participant observation. This was severely disrupted and delayed by the COVID-19 pandemic. Access to the group home was curtailed for a lengthy period of time and researchers were not considered essential workers. Derek was also considered to be an at-risk person. Researchers adopted a non-participatory approach as total bystanders at the group home and did not get involved in any direct provision of care or support. An observation template was designed by the research team to collect observational field notes about the RNs' practice together with field notes describing the context of that practice including answers to questions from the researchers such as "can you tell me why you just checked vital observations?" At each visit, all occurring during December 2020, the researchers signed into the group home's visitors' book after all COVID-19 screening checks (e.g., temperature) and signed declaration (e.g., any notable travel and quarantine) were completed. The researchers verbally greeted Derek, the staff and any other residents who were home, before commencing any observational data collection.

All observational data collection was conducted from a seat at a dining table located at the side of a large common room in which residents "hang out" together, listening to the radio or watching television. The space is large enough to accommodate five adults all of whom are non-ambulant and who remain in wheel- or comfort-chairs. The space included a kitchen, separated from the main space by a bench containing drawers facing into the kitchen. The RN and support workers used the kitchen to prepare modified meals (e.g., pureed/soft diet) for those residents who were not nil by mouth. The main collective activities of the house occurred in this common space including meal preparation, feeding, and medication administration.

Each resident had his or her own bedroom and the house contained two bathrooms to be shared by residents whose bedrooms were adjacent to the bathrooms in each wing of the house. No observations were conducted in Derek's bedroom or bathroom out of respect for his privacy, although activities in bedroom and bathroom were audible from the dining table. For example, Derek could be heard coughing, laughing, and vocalising during his shower. There were a total of six separate observation sessions conducted by NW, PL and ZL, all RNs and applied researchers with expertise in intellectual and developmental disability, and consisting of 30 h over a period of two weeks during December 2020. In total, five different RNs from the group home were observed working either morning ($n = 2$) or afternoon ($n = 4$) shifts. No observations were conducted on the night shift, between 2100 and 0700 h. Table 1 provides a demographic summary of the RN participants.

Table 1. Participant demographic data.

Participant Variable	<i>n</i> = 5
Gender	
Male	1
Female	4
Age (years) <i>M</i> (range)	52 (36–69)
Accreditation	
Australia	4
Overseas	1
Experiences working as Registered Nurse (in years) <i>M</i> (range)	22.4 (0.6–44)
Experiences working in current position (in years) <i>M</i> (range)	5.9 (0.6–22.5)
Experiences working with people with IDD (in years) <i>M</i> (range)	5.8 (0.6–22.5)
Experiences working with selected client in study (in years) <i>M</i> (range)	1.5 (0.1–3.5)

Literature review to build a comparison case. The hypothetical comparison case was intended to reflect the same profile as Derek using a compilation of published literature. In contrast to Derek, the comparison was hypothesised to live in a disability-specific group home staffed without any direct care and support from registered nurses. The literature search was conducted between September and November 2020. The specific strategy included relevant terms for intellectual disability/ies, terms for healthcare events (e.g., ambulatory services, emergency department, hospital admission, and length of stay), and terms for specific health conditions (e.g., asthma, aspiration, pneumonia, and constipation). The following databases were searched: Cochrane database, CINAHL, EMBASE, and Science Direct. Reference lists of relevant papers were scrutinised, as were citing papers. The initial search was conducted by ZL, with data extracted into an Excel spreadsheet for ease of organisation and analysis, with RR cross-checking the potential data. This was done so that the most linkable information could be identified to construct a comparative hypothetical case. Nevertheless, despite our best attempts to construct a meaningful and robust comparison case from the peer reviewed literature, a number of issues limited the possibility: a lack of precision in the literature about the demographic and diagnostic profile of research participants with intellectual disability (i.e., sex, age and primary diagnosis not reported), limited granularity about the context of care and support (i.e., type and size of accommodation setting), missing information and a lack of theorisation specific to models of care and support, and limited to no description of staff profiles who provide the care and support.

Consequently, instead of compiling a comparison case directly from the literature, we made some assumptions based on the available literature and documentation of Derek's care, to build scenarios of what the differences in Derek's resource uses, health outcomes and associated costs might look like with and without specialist support. In these scenarios we focussed on differences in hospitalisations associated with different levels of care. We built four scenarios. One illustrating Derek's actual RN time and hospitalisations, one looking at the expected differences if he were receiving ideal RN and expert Clinical Nursing (CN) time, and two assuming no RN or CN, but additional DSW support. The assumptions made in each of these scenarios are summarised in Table 2 below.

Table 2. Four care scenarios.

Scenario	Inputs	Outcomes	Supporting Evidence
1.	RN time currently receiving	2 hospital admissions via ambulance to ED, with average length of stay (ALOS) 3.5 days.	Actual documentation/file audit
2.	Additional RN time and CNS and CNE	1 hospital admission via ambulance to ED, no change to ALOS.	Ideal support based on RN-led, relationship centred care [10] plus costed hours for a CNS and a CNE. Assumed to halve the number of emergency hospitalisations.
3.	No RN or CN time. Additional AIN time in place of RN time currently receiving.	12 ambulance trips to ED, 4 admissions with no change to ALOS.	Documented frequency of oral suction which in the absence of specialist care would lead to 1 ED presentation per month. Assume this would double admissions from 2 to 4 per year. No change to ALOS (which is unlikely).
4.	No RN or CN time. Additional AIN time in place of RN time currently receiving.	12 ambulance trips to ED, 4 admissions with ALOS 27 days.	As above but with ALOS 27 days which is the mean length of stay in a UK study [26] for EDS related emergency hospitalisations for respiratory infections.

Health economic data. Nursing and disability support worker costs were obtained from the NDIS price guide 2020–21 (specifically V1.0.3, pages 48–49 and p. 39); Clinical Nurse Specialist (CNS) and Clinical Nurse Educator (CNE) are not itemised in the NDIS price guide so were costed at the rate of a CN, the Assistant in Nursing (AIN) was costed as a Level 2 DSW. The average cost per emergency presentation and per day in hospital in NSW were obtained from Round 22 of the National Hospital Cost Data Collection Report, specifically Tables 12 and 13 in the Appendices [27]. Ambulance costs were obtained from the NSW Ambulance accounts and fees schedule. We also identified costs of Derek’s medications, GP and allied health services use through the Pharmaceutical Benefits Scheme, Medicare Benefits Schedule and NDIS price guide. However, as we were unable to find suitable comparison data in the literature this information was not used in the scenarios, effectively assuming no change to these resources in each scenario. Unit costs for each resource were multiplied by the number of units of each resource (e.g., staff hours, days in hospital) to calculate the total cost of each scenario.

4. Results

4.1. The Case—Derek

Derek turned 53 years old during the time of recruitment and retrospective file audit data collection (July 2019–June 2020) and was born with profound intellectual disability, cerebral palsy (dysplastic quadriplegia) and blindness in both eyes. Like many of his contemporaries, at the age of three, Derek was admitted to a large residential complex that catered specifically for a range of children with intellectual disability and associated support needs. Although unable to mobilise due to multiple contractures, when Derek was a child, he was able to push himself around the residential unit on a specially designed skateboard-like device. Derek shared the same residential unit and grew up through adolescence and young adulthood with many of the same residents and staff until the residential complex closed when he was approximately 48 years old. He then spent two years in a transition cottage on the site of another large specialised residential complex before moving into a disability-specific group home, situated in a mid-suburban area of Sydney approximately 25 km from the Sydney CBD. Derek attends a disability-specific day program three days per week, travelling the 25 km to and from the day program in a taxicab without any staff support.

Derek shares group home accommodation with four other adults with intellectual disability and similar disability-associated chronic and complex health support needs. The

group home is staffed primarily by DSWs, with one registered nurse on each of three, eight-hour shifts, per 24 h period (morning, afternoon and night shift). The RN is not only responsible for all five of the residents of the said group home, but is also “on call” and expected to provide daily planned (e.g., insulin administration) and emergency support (acute exacerbation of a chronic illness) to five other adults with intellectual disability living in a neighbouring group home.

Derek requires full support for all of his daily care needs. He is not ambulant and requires a wheelchair for all mobility. He is nil by mouth with all nutrition, fluids and medications ($n = 7$) provided via parenteral feeding tube (gastrostomy). Unable to verbally communicate, Derek will communicate his emotions, such as happiness and pain, using facial expressions and non-speech vocalisations. Derek has epilepsy, dysphagia, reflux disease, chronic constipation, compromised respiratory function (including an inability to adequately cough and clear sputum), osteoporosis, scoliosis, and multiple joint contractures. In addition to the medications administered parenterally, Derek has daily topical medications for dry skin and skin rashes related to allergies, as-needed respiratory and bowel medications, and twice-yearly injections of a medication to increase bone mass in males.

Derek’s main health risk is from aspiration of saliva and/or stomach contents into his respiratory tract where aspiration pneumonia can develop and escalate rapidly; during the file audit time period (July 2019–June 2020) Derek had two hospital admissions for aspiration pneumonia. Boxes 1 and 2 provide paraphrased progress notes related to the antecedents and registered nurse led care—assessment, intervention, monitoring, decision making—for each of these two hospitalisations.

Box 1. Hospitalisation for aspiration pneumonia—3 days * in October/November 2019. (* Each “day” is defined by the number of overnight stays.)

From 0330 hrs, Derek began being noisy, appeared anxious with his face becoming red with moist coughing at times and crackling breathing sound. Respirations at a regular rate with noted shivering of his body. Remains alert and responded to staff interaction. Temp was 36.9 °C at 0345 hr, PRN Panamax Elixir 20 mL given at 0350 hr via PEG tube with head elevated up high. PRN Ventolin 5 mg also given at 0355 hr via Nebuliser. Pulse checked and increased rapidly to over 120 bpm. O₂ Saturation at 93%, unable to check BP because pulse too high and on alert so the BP machine will not take a valid reading. Bowel also opened at 0400 hr. Continued to deteriorate, at 0410 hr contacted 000 for medical attention. Ambulant Medical Team arrived at 0430 hr, more observations: pulse remains high and slight fever with Temp 37.4 °C, commenced on O₂ therapy via Nasal prong then transferred to hospital from 0455 hr for further investigation. At 0500 hr person responsible (sister) informed; incident report completed.

Box 2. Hospitalisation for aspiration pneumonia—4 days * in December 2019. (* Each “day” is defined by the number of overnight stays.)

From 0100 hrs, Derek noted to start heavy snoring-like breathing. Vital observations taken: respiration rate = 24 per minute; O₂ saturation = 98% on room air, and core temperature noted to be a little high at 37.5 °C. At 0110 hrs, Derek was repositioned to high fowlers to aid the opening of his airways, with PRN Ventolin 5 mg given via nebuliser with nil effect noted to breathing. Face noted to be flushed, temperature retaken, now noted to be 38.0 °C. Derek also noted to be slightly restless and vocal, with heavy breathing continuing. Respiration rate remains at 24–25 breaths per minute and O₂ saturation at 97–98% on room air. BP taken = 131/63, pulse rapid at 115 beats per minute. Over the next hour, monitored for signs of deterioration, tepid sponge given to reduce temperature and to enhance comfort with nil effect. At 0210 hrs PRN paracetamol elixir given 20 mls via PEG to reduce temperature. At 0245, condition remained unstable, booked ambulance for hospital transfer for further investigation and more aggressive treatment. At 0245 hrs, the ambulance arrived.

4.2. Non-Participant Observations

4.2.1. Morning Shifts ($n = 2$: Ongoing RN $n = 1$, Agency RN $n = 1$); Italicised Content Represents Verbatim Fieldnotes

RNs were busy with a range of duties and with other residents, there were few extended periods of interaction between Derek and the RN. On both occasions, RNs attended to Derek's gastrostomy feeds; because of his high risk of aspiration, Derek's gastrostomy feeds were suspended by the RN before any physical activity, personal care or bathing was undertaken. The RN also administered Derek's medication. RNs intervened in Derek's condition once during each shift. Both incidents were quickly and easily resolved and had no observable, ongoing adverse consequences. One RN intervened during a period of coughing that had the potential to threaten the integrity of Derek's airway:

0714—Derek started to cough—loose productive cough. RN conducted immediate assessment, Derek not distressed at all, but RN stopped enteral formula. Derek stopped coughing within 10 s, appeared to self-clear his airway and swallow saliva/expectorate. Temperature taken—afebrile. Enteral formula re-started after 5 min of no coughing.

Only RNs took responsibility for suspending and recommencing Derek's enteral feeds and for assessment of his gastrostomy site. Both shifts were observed to be conducted efficiently and effectively: "RN noted to be incredibly efficient, and just getting on with stuff, multi-tasking" and "The observation period continued in an orderly manner. It was remarkable how controlled and well organised the house appeared." The proactive approach adopted by the ongoing RN, contrasted with the more reactive approach to the shift adopted by the agency RN, who, although capable and experienced, was unfamiliar with Derek and the other residents in this group home. This was observable in who 'took charge' of each shift. When the agency RN was present, it was an experienced DSW who directed the activities of the shift because of her high degree of familiarity with the residents and the routines of the household.

4.2.2. Afternoon Shifts ($n = 4$: Primary RN $n = 1$, Ongoing RN $n = 1$, Agency RN $n = 2$)

All four periods of observation included at least one instance when the RN recorded Derek's vital signs, when the RN suspended Derek's feeds in preparation for his shower, and when the RN administered Derek's medications. On two separate occasions, Derek experienced periods of respiratory distress characterised by persistent, at times paroxysmal, coughing upon his transfer from his taxicab into the house after being at the day program. The following extracts provide illustrative examples of the types of intervention undertaken:

"1610, moist, productive coughing episodes . . . registered nurse suctioned about 20 mL from Derek's oropharyngeal cavity"; "1624, registered nurse observing for any deterioration in respiratory status"; "1632, more coughing and appearing to gag, registered nurse in attendance 1:1 providing reassurance and assessing respiratory status. More suctioning of mouth cavity to help Derek remove expectorate from mouth. RN also took observations—oxygen saturations, pulse and respiration rate (all within normal limits)"; "1703, More verbal interaction with Derek, assessing his status to determine if he is stable enough to have a shower, which involves lying virtually flat for a short period of time on the shower trolley. Registered nurse issued instruction to support worker about Derek's shower and the timing"; and "1708—some more coughing, but not distressed—registered nurse decided to be the second staff member to help Derek's transfer for his 2:1 shower rather than the second support worker, in relation to Derek's respiratory status.

During the first hour after Derek's return home from his day program, as described in the field note above, the RN was in constant attendance, assessing Derek's respiratory status and intervening to maintain his airway. Taking careful steps to avoid exacerbating Derek's distress, the RN would suspend Derek's PEG feeds for a longer period than usual and by delaying the timing of his shower until his condition stabilised. The RN continued to monitor Derek's vital signs during the evening and made explicit her intention to report the unusually long period during which his PEG feeds were suspended to the house

manager and to the dietician because of the reduced level of caloric intake rather than the reduced volume of fluids that Derek had received.

4.2.3. An Avoided Hospitalization—July 2020

With other research activities that relied on interaction with Derek limited by COVID-19, the file audit period was extended with the permission of the institutional HREC and the partner organisation. In July, 2020, Derek experienced a rapid deterioration in his health status due to respiratory distress, of a similar pattern to previous respiratory-related hospital admissions. Box 3 highlights paraphrased excerpts from the registered nurse's progress notes describing a range of highly skilled decision-making in the form of nursing observations, assessments, interventions, and evaluations.

Box 3. Avoided hospitalization—July 2020.

Since 1740 Hrs, began some moist coughing and gurgle sounds. The breathing noise began to be louder and more frequent, at 1800 h vital observations were: BP 130/85 mmHg, Pulse 108 BPM, Respirations 28 RPM, Temperature 36.8 °C, O₂ saturation 90% in room air. PEG feeds stopped. Oral suctioning with Yankauer tube attended as per respiratory support plan. Approximately 70 mL of mucous obtained from suctioning. O₂ saturation dropped to 89%; oxygen therapy at 4 L/min given via mask as per respiratory management plan. From 1830 Hrs onwards, coughing stopped with breathing sounds returning to normal. However, as O₂ saturations remained low, oxygen therapy continued until 1930 h when O₂ saturations returned to 97%. Remains settled and resting in comfort chair, however PEG feeds discontinued for the night (total nutrition given today: 650 mL). Vital observations monitored for the rest of the night. Sleeping soundly and comfortably in bed at the end of the shift.

4.2.4. A Further Hospitalisation for Aspiration Pneumonia—11 Days * in August 2020

Two weeks after the rapid deterioration noted in Box 3, when a potential hospitalisation was avoided, Derek was admitted to hospital. The same highly skilled decision-making and series of nursing observations and interventions documented in Box 3 did not have the same effect on Derek's health and his respiratory function became further compromised. By the time of the scenario described in Box 4, Derek had been prescribed overnight oxygen via nasal prongs to keep his blood oxygen saturations above a satisfactory level (i.e., 90% O₂ Sat. as measured by a pulse oximeter). Box 4 highlights paraphrased excerpts from the registered nurse's progress notes.

Box 4. Hospitalisation for aspiration pneumonia—11 days * in August 2020. (* Each "day" is defined by the number of overnight stays.)

Slept very comfortably in his wheelchair until 1900 hrs when coughed and vomited about 30 mls of PEG feed. Feed stopped immediately after that (710 mls of feed given up to this time). Observations at 1920 hrs: BP 105/60, Pulse 89, O₂ saturation 95% in room air, respirations 25 RPM. Coughing, attempted to suction out saliva using Yankauer suction, but nothing came out, in fact he got increasingly anxious, so suctioning ceased. PRN Ventolin administered at 1925 hrs to help open airways, with good effects; settled for a while, although still coughing on and off. Health status quickly declined and started having unusual breathing at around 1940 hrs: Respiration 34 RPM so transferred to upright position in bed so that he can relax. Observations at 1945 hrs: O₂ 89% in room air, respiration 36 RPM, Pulse 115 BPM, BP 136/70. Started on 3 L of O₂ via mask. Looked in pain, abdomen sore? O₂ saturation increased to 94% on 3 L of Oxygen. Called additional RN for added nursing assessment; called Ambulance around 2005 hrs. Observations at 2020 hrs: BP 146/70, respirations 39 RPM, Temp 37.1 °C, pulse 110, O₂ saturation 93% at 3 L Oxygen via mask. Ambulance arrived at 2050 hrs; transferred to hospital. Sister informed via phone, incident report completed.

The four documented incidents provided here describe the most serious compromises to Derek's health during an 18-month period from July 2019. These key incidents, and information about the average RN time he receives per day, enable a calculation of the

financial cost of Derek's care and provide evidence of the escalation of costs of his care when his health is severely compromised.

4.2.5. Financial Costs

A range of financial costs associated with Derek's health resource use and support across a 12-month period (July 2019–June 2020) were calculated. All costs reported are in Australian dollars, which at the time of publication one hundred Australia dollars (AUD 100) equates to approximately USD 73.00, GBP 53.00, and EUR 62.00. Medical and allied health-specific costs were tallied as follows: pharmaceutical costs totalled AUD 4658; 52 GP visits to Derek's home at AUD 80.48 each were costed at AUD 4185; Allied health home visits (Occupational therapist ×2, podiatrist ×4, speech pathologist ×1, dietitian ×2, and physiotherapist ×1) were costed at AUD 1940; medical consultant visits at a range of clinics/hospitals (respiratory physician ×2, neurologist ×1, dental ×1, orthoptist ×1, and done density scan ×1) totalled AUD 836. The grand total of these medical and allied health-specific costs came to AUD 11,619. These were assumed to be the same in each scenario below and hence excluded from the comparison analysis.

Table 3 provides a detailed breakdown of the various types of supports provided for Derek and the costs of these, presenting four scenarios that represent different models of care and their associated costs. Scenario 1 is based directly on Derek's observed costs for the model of care he currently receives. At present, the RNs not only work 8 h shifts providing all of the direct care and leadership of the staff team, but also make time within these shifts to conduct assessments, develop plans of care, and train DSWs. Further, no registered nurse attends any medical consultation or other appointment outside of the home setting. Scenario 2 is a model based on an ideal scenario where Derek not only has access to an RN for his daily care and support needs, but also to a funded CNS/CNE for expert care management, health assessment and planning, attendance at medical consultant appointments with Derek, and a completed staff education plan that is Derek specific. Scenario 3 assumes that a Level 2 DSW (with a Certificate III or IV in disability work as a minimum level of qualification) will entirely replace the registered nurse in the current model of care and support offered to Derek with a hypothesised increase in the number of hospitalisations. Scenario 4 builds on scenario 3 with the addition of a hypothesised increase in the average length of stay (ALOS) in hospital for people with significant mealtime supports and a history of respiratory infections, partly related to presenting at the emergency department later than is ideal and partly related to the group home not being able to offer care and support until a full recovery was observed [26].

Table 3. Summary of the Four Scenarios.

Health Service Type	Scenario 1: Derek's Actual Observed RN Time (Hours Per Week) and Hospitalisations			Scenario 2: Ideal RN+CNS/CNE Time (Hours Per Week) and Hypothesised Reduction in Hospitalisations		Scenario 3: No RN or CNS/CNE, Additional DSW Time and Hypothesised Increase in Hospitalisations		Scenario 4: No RN or CNS/CNE, Additional DSW Time and Hypothesised Increase in Hospitalisations and ALOS	
	Unit Cost (Per Hour Unless Otherwise Specified) (AUD)	Health Service Use	Health Service Cost Per Annum (AUD)	Health Service Use	Health Service Cost Per Annum (AUD)	Health Service Use	Health Service Cost Per Annum (AUD)	Health Service Use	Health Service Cost Per Annum (AUD)
RN weekdays daytime	107.25	6.25	34,856.25	8.01	44,671.77	N/A	0.00	N/A	0.00
RN weekdays evening	118.31	6.25	38,450.75	6.42	39,496.61	N/A	0.00	N/A	0.00
RN weekdays night	120.51	6.25	39,165.75	6.42	40,231.06	N/A	0.00	N/A	0.00
RN Saturdays	153.05	3.75	29,844.75	3.84	30,561.02	N/A	0.00	N/A	0.00
RN Sundays	175.95	3.75	34,310.25	3.84	35,133.70	N/A	0.00	N/A	0.00
Additional DSW time (hours per week) weekdays daytime *	58.68 (L2)	N/A	0.00	N/A	0.00	6.25	19,071.00	6.25	19,071.00
Additional DSW time (hours per week) weekdays evening	64.59 (L2)	N/A	0.00	N/A	0.00	6.25	20,991.75	6.25	20,991.75
Additional DSW time (hours per week) weekdays night	65.77 (L2)	N/A	0.00	N/A	0.00	6.25	21,375.25	6.25	21,375.25
Additional DSW time (hours per week) Saturdays	82.32(L2)	N/A	0.00	N/A	0.00	3.75	16,052.40	3.75	16,052.40
Additional DSW time (hours per week) Sundays	105.96 (L2)	N/A	0.00	N/A	0.00	3.75	20,662.20	3.75	20,662.20
CNS weekdays	124.05	N/A	0.00	N/A	32,317.51	N/A	0.00	N/A	0.00
CNE weekdays	124.05	N/A	0.00	N/A	6450.60	N/A	0.00	N/A	0.00
Ambulance journeys per year	786 callout plus 7.09 per km for 7 km	2	1671.26	1	835.63	12	10,027.56	12	10,027.56
Emergency presentations	957 per presentation	2	1914.00	1	957.00	12	11,484.00	12	11,484.00
Hospital admissions per year	1825 per day	2; ALOS 3.5 days	12,775.00	1; ALOS 3.5 days	6387.50	4; ALOS 3.5 days	25,550.00	4; ALOS 27 days	197,100.00
Total cost of nursing plus hospitalisations			192,988.01		237,042.39		145,214.16		316,764.16

* Additional DSW time for Scenarios three and four where there is no registered nurse. Scenario 1 versus Scenario 2: Net cost of AUD 44,054.38 for the ideal scenario with additional specialised nursing support compared to the current scenario—improved quality of life and reduced probability of avoidable death are both expected. Scenario 1 versus Scenario 3: Net cost of AUD 47,773.85 for the current scenario with RN support compared to usual care (assumes usual care incurs increased hospitalisations but no change in average length of stay, which is unlikely). Scenario 1 versus Scenario 4: Net benefit (cost savings) of AUD 123,776.15 for the current scenario with RN support vs. usual care (assumes usual care incurs increased hospitalisations and length of stay). Scenario 2 versus Scenario 4: Net benefit (cost savings) of AUD 79,721.77 for the ideal scenario compared with the most likely usual care (increased hospitalisations and length of stay).

5. Discussion

Derek's diagnoses and support needs are extremely common among ageing adults with profound intellectual disability, a secondary disability and multiple chronic and complex health problems [25]. A recent report into deaths of people living in Australian disability services, noted case studies very similar to Derek, but with major gaps in service provision and managing deteriorating health, such as managing the risks of and responding to events where a person is choking [6]. A registered nurse led model of care and support is likely to avoid many of these identified problems. The paraphrased progress notes and non-participant observation fieldnotes offer a glimpse into the specialised care and management of Derek when his health deteriorates rapidly and seriously. However, they do not fully capture the cycle of observation, assessment, intervention and outcome evaluation that underpins clinical decision making central to the work that RNs perform [28], nor the broad spectrum of tasks undertaken and knowledge and skills applied by RNs caring for people such as Derek on a shift-by-shift basis [12]. Caring for Derek, and people with similar diagnoses and support needs, requires detailed knowledge of human body systems and the interactions between them, pathophysiological pathways and the ways that chronic illness/es can cascade rapidly during an acute exacerbation, the action and interaction of multiple pharmacological agents, and critical insight into the nursing interventions and clinical decision making needed. Although the scope of practice of Australian DSWs has been expanding in response to the needs of people with intellectual disability after deinstitutionalisation [29], what was described above in the progress note and observation summaries is not only well beyond the scope of a DSW, but also any allied health worker. Despite skilled physiotherapists having competencies for chest physiotherapy and oral suctioning, even if this was funded for Derek to be performed each afternoon when arriving home from his day program, a physiotherapist does not have other RN-specific skills and if RNs were removed entirely to be replaced by 1 h of daily chest physiotherapy, the risk is that at 3 a.m. there is no one in attendance who can provide targeted and timely care to Derek. Put succinctly, just as there is a price to every decision about care and support, there is also a risk, and crucially it is not Derek who gets to make that decision, rather this is left to others who do not have to bear the ultimate cost.

In addition to medications, GP consultations and allied health services appointments, which total less than \$12,000 per year, most of the financial costs of Derek's care can be apportioned between two organisations; the ongoing costs of care to a disability service and the cost of emergency department presentations and hospitalisations to the acute health care sector. Results of our analysis of the financial costs associated with the care of Derek clearly demonstrate that the financial cost to a disability service for RNs and CNS/CNEs in Scenario 2, what we refer to as an ideal scenario that fully acknowledges Derek's disability-related health needs, is higher than the financial cost of DSWs in Scenarios 3 and 4—as is to be expected. It also suggests that the financial cost saved by the disability service in Scenarios 3 and 4 is shifted to the acute health care service, through increased emergency presentations and admissions. This shift might have some benefits for the disability service, for example, by making the disability service more financially sustainable. However, shifting expenses to the acute health care sector is potentially disadvantageous to that sector, for example, in terms of patient load, and to the tax payers who fund it. Either way, the financial cost of care does not disappear, it is simply redistributed between services. When the ideal scenario (Scenario 2) is compared with the most likely usual care scenario (Scenario 4) there is an overall net benefit of almost \$80,000. This is because the additional cost of care to the disability service is more than offset by the costs savings from reduced emergency presentations, hospitalisations and average length of stay. This suggests that decision making about resourcing of disability services needs to be undertaken holistically as it affects both disability and health services.

Our calculations add a dimension to what is already known about the cost of care for people with intellectual disability. Studies conducted in Australia to calculate the costs of care for children with intellectual disability have calculated costs to families, communities,

and government. For example, the costs incurred by parents of caring for their children with intellectual disability in terms of outlay and lost opportunity to work for an income have been calculated [30]. The costs to parents, whose children lived in the family home, were significant despite the inclusion in the calculation of government carer allowances and without the financial cost of paid carers such as nurses. More recently, the high cost of care for children with intellectual disability has been calculated in some detail [31]. The financial cost of a wide range of health care workers and therapists was calculated, including the cost of dentists, counsellors, naturopaths, social workers, and hospital services. However, the cost of nursing care was again absent from the calculation or subsumed into the costs of hospital presentation and hospital services and apportioned using the broad categories of individual, government, and society. Although these two examples relate to the care of children, many of whom reside with their parents rather than in group home settings, the point is that costs have been calculated on a macro level when micro level interventions, such as the provision of nursing care, might be what makes a difference to the life and health of a given individual. More importantly, the cost of the ill-health suffered by the client transcends the financial cost to the disability and/or acute health care services. The UN Convention on the Rights of Persons with Disabilities identifies that people with disabilities have a right to health [32]. In support of this, the NDIS states that people with disabilities have a right to quality care and support [33]. The NDIS is pushing for a delegated model of registered nursing care (akin to attendant care and aligned with social model of disability), where RNs delegate tasks to DSW [34]. We contend that a delegated model of care for people such as Derek not only lacks any evidence [16], but also does not fulfil the client's right to quality care and support, and, therefore, infringes the client's right to the best attainable health. One way to ensure that client's rights can be protected and their optimal health maintained is through the institution of Intellectual Disability Nurse Specialists, as costed by us in scenario 2. Intellectual Disability Nurse Specialists have been shown to be effective in promotion person-centred care, facilitating systems co-ordination, and conduct professional development activities to enhance the knowledge and skills of a range of health care professionals for the benefit of clients and their families in the UK [35]. The equivalent Australian nursing role of Disability Nurse Navigator has proved to be an effective support for people with intellectual disability who might otherwise experience compromises to their health due to changes in service delivery models, for example, the expansion of telehealth, necessitated by the restrictions imposed in response to the COVID-19 pandemic [8]. A delegated care model might be justified by the financial saving to the disability service, as outlined in Scenarios 3 and 4, but it is difficult to justify in terms of the health and wellbeing of an individual client such as Derek and cost shifting to the health sector. Recent research evidence suggests that people with intellectual disability and multiple chronic and complex conditions are at increased risk of adverse health outcomes associated with hospitalisation compared to other patient populations [1,36,37]. Our assumption of increased exposure to risk in the acute health care setting is embedded in our calculations for Scenarios 3 and 4. The financial savings made by the disability service in Scenarios 3 and 4 must not only be offset against the increased financial costs to the acute health care sector, but also against the cost in terms of health and wellbeing of the disability services' clients.

Our analysis further suggests that the care of people with profound intellectual disability and multiple chronic and complex conditions is delivered at a nexus between economic rationalism and full participation. The NDIS seeks to ration care using an approach of differentiation in which all people with disabilities are assumed to have equivalent physical and intellectual capacity to make decisions about and to manage their own care [14,38]. The underlying assumption is false and can have severe adverse consequences—including potentially avoidable death—for people with profound intellectual disability. It is only through the introduction of differentiation into the system that resources can be allocated equitably. There are people with intellectual disability and multiple chronic and complex conditions that require high levels of care and support to maintain their health. People

who have severe limitation of mobility and communication are at high risk of being excluded from society if their health cannot be maintained. Such people have no hope of participating fully without access to highly skilled and knowledgeable RNs to co-ordinate, manage, and deliver their care.

The Disability Royal Commission perpetuates the assumption of equivalent capacity in its issues paper "Promoting Inclusion" [39]. For example, two barriers to inclusion that are listed by the Royal Commission are "... not recognising the right of people with a disability to have choice and control over their lives ..." (p. 3) and "supports that are only provided in settings that are separate or segregated from the community or general services." (p. 3). Our study is one of people with profound intellectual disability and multiple chronic and complex conditions for whom choice and control are almost non-existent and for whom relevant degrees of separation and segregation might be necessary in order to provide the degree of care and support that they need. Recent research has highlighted that such care can be provided by highly trained RNs [11]. Highly developed communication skills, supportive interventions for health and well-being, and the development of specialized nursing roles in the field of intellectual disability all have the potential to maintain and optimize health and promote participation among people with intellectual disability regardless of their degree of disability or their residential circumstances [11].

6. Limitations

The major limitation of this study is that it is a single case study and despite such an approach having strengths with respect to reliability, it is limited, and so future studies must utilize multiple cases as applying a health economics lens to the care of people with intellectual disability is further refined. It is hoped that the next phase of this research will not be hampered by the COVID-19 virus where access to recruitment and the participation of people with intellectual disability who have vulnerable health status was almost impossible. Derek is not an amalgam of multiple, typical cases of people with intellectual disability, he is a unique individual and, as such, is potentially identifiable from the information that we have presented in this paper. Derek's sister, his next of kin, consented to our inclusion of Derek in our study with an understanding that his identity could potentially be revealed. Our inclusion of Derek is justified by the high degree to which his personal situation conforms to the situations of others with profound intellectual disability and multiple chronic and complex conditions. Our original intention was to compare Derek's case with that of another individual living in similar circumstances with a similar degree of intellectual disability, but with less access than Derek to care provided by an RN. This was not possible because of the absence of any suitable individual from residences within the partner organisation and because of the limitations of COVID-19 which prevented us from searching for a comparable case in other disability services. The comparisons derived from a survey of the literature do not offer the same fidelity as a comparison between two real-life individuals, but the comparison that they do provide is based on research evidence and provides a plausible point of comparison with Derek's case. Nevertheless, that we have incorporated multiple sources of data, and in particular used non-participant observation as a means to give Derek some agency beyond a file audit, adds to the robustness of this study and offers methodological guidance on taking the next research steps. As this single case resided in Sydney, Australia, there is also the limitation of being unable to generalise the findings to other geographical and health/social care contexts.

7. Conclusions

Based upon this single case study, the economic evidence suggests that appropriate quality care provided by disability services can produce overall cost savings to government through reduced emergency presentations and hospitalisations. More importantly, the patient's quality of life improves, and risk of avoidable death reduces. Therefore, consistent with upholding the right of people with disabilities to quality care and support, disability

services should be appropriately funded to provide specialist nursing support to people with intellectual disability and complex support needs, such as Derek.

Author Contributions: Conceptualization, N.J.W., R.R., Z.L. and P.L.; methodology, N.J.W., R.R. and P.L.; software, R.R.; validation, N.J.W. and P.L.; formal analysis, N.J.W., R.R. and P.L.; investigation, N.J.W., P.L. and Z.L.; data curation, N.J.W.; writing—original draft preparation, N.J.W. and R.R.; writing—review and editing, P.L. and Z.L.; project administration, Z.L.; funding acquisition, N.J.W. and P.L. All authors have read and agreed to the published version of the manuscript.

Funding: This research was funded through a partnership grant between the School of Nursing and Midwifery at Western Sydney University (50%), Achieve Australia (25%), and the Professional Association of Nurses in Developmental Disability, Australia (PANDDA) Inc. (25%).

Institutional Review Board Statement: The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Ethics Committee of Western Sydney University (H-13526 on the 29 October 2019).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: The data presented in this study are available within this article.

Acknowledgments: We acknowledge the support of the registered nurses who helped us to navigate the various gatekeepers during recruitment.

Conflicts of Interest: During the course of this research, Associate Professor Wilson was elected as President of PANDDA, however was absent from the executive meeting and decision making with respect to supporting and co-funding this research.

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