

Health information infrastructure for people with intellectual and developmental disabilities (I/DD) living in supported accommodation: Communication, co-ordination and integration of health information

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Abstract

People with intellectual and/or developmental disability (I/DD) commonly have complex health care needs but little is known about how their health information is managed in supported accommodation, and across health services providers. This study aimed to describe the current health information infrastructure (i.e., how data and information are collected, stored, communicated, and used) for people with I/DD living in supported accommodation in Australia. It involved a scoping review and synthesis of research, policies, and health documents relevant in this setting. Iterative database and hand searches were conducted across peer-reviewed articles internationally in English and grey literature in Australia (New South Wales) up to September 2015. Data were extracted from the selected relevant literature and analysed for content themes. Expert stakeholders were consulted to verify the authors' interpretations of the information and content categories.

The included 286 sources (peer-reviewed $n = 27$; grey literature $n = 259$) reflect that the health information for people with I/DD in supported accommodation is poorly communicated, coordinated and integrated across isolated systems. 'Work-as-imagined' as outlined in policies, does not align with 'work-as-done' in reality. This gap threatens the quality of care and safety of people with I/DD in these settings.

The effectiveness of the health information infrastructure and services for people with I/DD can be improved by integrating information sources and placing people with I/DD and their supporters at the centre of the information exchange process.

People with I/DD in supported accommodation: health inequities and health information management

People with intellectual and developmental disabilities (I/DD), who have lifelong limitations in intellectual functioning and adaptive behaviour, including conceptual, social and practical skills (American Association on Intellectual and Developmental Disabilities, 2010), commonly also have complex health care needs (Cocks, Thomson, Thoresen, Parsons, & Rosenwax, 2016). They are significantly higher users of multiple health services than their peers without I/DD (Van Dooren, Lennox, & Stewart, 2013). Of the 82,125 Australians with I/DD who use government services, the majority (64%, $n=52317$) live in private residences. The second largest group (22%, $n=17721$) live in supported accommodation (Australian Institute of Health and Welfare (AIHW), 2015). Supported accommodation provides up to 24-hour support and includes domestic-scale facilities shared by up to seven individuals with I/DD and their direct support workers (DSWs) who may reside on or off site. Larger facilities provide supported accommodation for more than seven residents (AIHW, 2016).

Compared to the general population, individuals with I/DD are at higher risk of having long-term conditions (e.g. diabetes, epilepsy) leading to lifelong interactions with multiple health professionals that increase in frequency and duration as people with I/DD age and experience functional decline (Cocks et al., 2016; Van Dooren et al., 2013). People with I/DD encounter inequities in access to health care and public health interventions resulting in poor health outcomes such as higher rates of hospitalisation and mortality (Florio & Trollor, 2015). These problems with access to health care are exacerbated by disjointed health care systems where communication, coordination, and integration of information are often lacking both at an individual level (i.e. between the person and health service providers) and at the systems level (i.e. across institutional and professionals' domains and jurisdictions; Bansler & Kensing, 2010; Bjørn & Kensing, 2013; Van Dooren et al., 2013).

In supported accommodation, and for the purpose of this review, health information incorporates (i) medical records, and (ii) service policies and documents used to prescribe, record or communicate health-related information within or across accommodation and health services. People with I/DD commonly rely on both DSWs and family members to meet their health support needs. These needs include their access to health services, inclusion in public health initiatives, and understanding of their own personal health information (Iacono, 2010; Wallace & Beange, 2008). Yet, there is little information in the literature about how the health information of people with I/DD is managed in supported accommodation settings or across different service sites or providers. It is not clear how people with I/DD engage in storing or sharing their own health information with multiple health service providers (Hemsley et al., 2015; Hemsley et al., 2016). International and Australian health care strategy reports (Australian Commission on Safety and Quality in Healthcare, 2012; World Health Organisation (WHO), 2015) have called for the adoption of integrated, coordinated, and collaborative healthcare systems that are more accessible to and sustainable for people with complex or chronic health conditions. Current initiatives in e-health such as the electronic personal health records (PHR) (e.g., the Australian My Health Record (MyHR)], Commonwealth of Australia, 2015a) could (i) facilitate the coordination of information across organisations, (ii) promote better integrated person-centred care, and (iii) help to ensure the continuity of care and the quality and safety of healthcare for people with I/DD (Bansler & Kensing, 2010; Hemsley et al., 2016; Hordern, Georgiou, Whetton, & Prgomet, 2011).

Information infrastructure in supported accommodation

Information infrastructures (i) include the technical, social, and organisational components that underpin today's complex health information systems; and (ii) describe how data and information are collected, stored, communicated, and used. Health information

infrastructure components include organisational regulations (e.g. policy, accountability, legislation), social relationships (e.g. between patients and health services, work practices), and technology (e.g. hardware, software, PHRs; Bjørn & Kensing, 2013; Sittig & Singh, 2010). Investigating information infrastructures reveals connections between technology and the organisational and relevant social settings (Bjørn & Kensing, 2013; Sittig & Singh, 2010). The Australian MyHR is an example of a digital health information infrastructure built upon and affected by all of these components (Commonwealth of Australia, 2015a).

Additional considerations and adaptations of digital health systems are required for populations with communication disability who have complex health needs and use a range of health services (Hemsley et al., 2016; Van Dooren et al., 2013). Currently, the nature and function of documentation for people living in supported accommodation settings are not well researched or understood (Quilliam, Bigby, & Douglas, 2015). Little information exists in the literature about how current paper-based information management systems in supported accommodation settings integrate with or adapt to new digital health information infrastructures. In supported accommodation, the use of documentation and the successful implementation of PHRs hinges on the development and maintenance of an appropriate information infrastructure that bridges *local* structures (e.g. policies and procedures for quality and safety in disability services) with *global* or organisational structures (e.g. organisational policy or legislation governing the health care system and disability support) (Piras & Zanutto, 2010; Quilliam et al., 2015). It would thus be beneficial to examine the current health information infrastructure (Piras & Zanutto, 2010) in supported accommodation, to understand how health information is currently managed, stored, and shared among relevant stakeholders, and how it impacts health information exchange in supported accommodation. Therefore, the aims of this study were to (i) conduct a scoping review and synthesis of relevant research, policies, and health documents on the use of health

documentation for people with I/DD living in supported accommodation in Australia; and (ii) describe the current health information infrastructure in supported accommodation.

Method

In September 2015, we conducted a search of (i) scientific databases for peer reviewed literature relating to health information infrastructure in supported accommodation settings for adults with I/DD, and (ii) organisational websites for relevant grey literature including legislation, policy documents, key agency reports and documents used in supported accommodation. We included a variety of evidence types across qualitative and quantitative research studies, governing or frontline documents (e.g. policies or documents used in the home), and reports of lived experiences (e.g. Commonwealth of Australia, 2015b). In November 2016, we repeated the search for grey literature after one key organisation updated numerous policy, procedure, and practice documents.

Search methods

First, we searched four scientific databases (PsychInfo, CINAHL, Web of Science, and Medline on Ovid and EBSCO platforms) and key journals for peer-reviewed publications published between 2000 and 2016 using a combination of keywords related to *people with I/DD living in supported accommodation* (e.g. supported living, group home), their *carers* (e.g. family, carer, direct support worker) and the current *information infrastructure* in supported accommodation (e.g. individual plans, incident reports, medical records, policy, guidelines).

Second, we conducted a hand search of the references in relevant identified peer-reviewed studies. Third, we sought context-rich detail from practice-based literature. We identified disability organisations in Australia to locate examples in the grey literature of (i) national legislation and policy (e.g. the National Standards for Disability Services (Department of Social Services, 2013)); (ii) reports from healthcare advisory agencies (e.g.

Agency for Clinical Innovation, 2015), consumer and advocacy groups (e.g. senate inquiry; Commonwealth of Australia, 2015b); and (iii) service provider policies and accompanying documents used by a state-level agency overseeing providers of supported accommodation (Ageing Disability and Home Care (ADHC), within the NSW Department of Family and Community Services).

As reported in previous research (e.g. Quilliam et al., 2015), we noticed early on in the process of sourcing, reading, and selecting grey literature that there was a large amount of documentation developed for use in government-managed disability accommodation services. Consequently, we decided to limit the scope of the review of documents in the grey literature to literature appearing: at a national level to Australia (e.g. National Disability Strategy, 2010–2020 (Commonwealth of Australia; 2011)); at a state level to NSW; and at an organisational level by selecting one key government agency overseeing supported accommodation services within NSW (Ageing Disability and Home Care, ADHC). In this way we developed an illustrative example of one state of Australia to reflect the wide range of document types and purposes of use in supported accommodation for adults with I/DD.

Data extraction and coding

The first author conducted and integrated the search results into the review based on a reading of title, abstract, and full text of sources and discussions with the second and fifth authors. The following data were extracted from the included sources into an Excel spreadsheet for a preliminary content analysis: (i) the format and type of documentation in supported accommodation (e.g. written, pictorial, or electronic; related to health records, individual plans, incident reports, or administrative documents), (ii) avenues for information exchange within and outside of the accommodation, and (iii) impacts and outcomes discussed in relation to use of documentation. Sources were classified according to whether they addressed the topic of documentation either directly or indirectly. Sources were classified as

direct if the source itself was a document; if the source reflected that documentation was the major focus and discussed in detail (e.g. main topic, major finding); or if documentation was identified as a requirement in policy or procedures. Sources were classified as indirect when documentation was only a marginal topic (e.g. coincidental finding) or not discussed in detail.

Analysis

An iterative process of data extraction and analysis across sources was conducted in a constant comparative manner as sources were collected and reviewed. After data extraction was completed, the first author analysed the data applying inductive and interpretive coding methods, first using open coding and then building categories and themes emerging from the identified sources and extracted data (Patton, 2015), and discussed these categories and themes with the second and fifth authors. To verify researcher interpretations of the data extracted, and the findings of the review, the first author drafted a model incorporating the thematic categories proposed to capture the state of documentation in supported accommodation; and further discussed the emerging themes with the other authors and experts in the field: two key academics separate from the research team, scholars on supported accommodation for people with disability, two disability advocacy groups - one in NSW and one national group, and one organisation overseeing supported accommodation in NSW. The first author kept a research log in the form of field notes of these consultations for discussion with the research team and used this information to finalise the model.

Results

Search results and characteristics of included sources

The three search phases resulted in the inclusion of 286 sources (peer-reviewed $n=27$; grey literature $n=259$) as follows: (i) the peer-reviewed literature comprised journal articles ($n=25$), one conference presentation and thesis each; and (ii) the grey literature comprised national and state level legislation or frameworks ($n=11$), policy, procedures or guidelines

($n=16$), and associated documents ($n=12$); reports from independent state level authorities and disability advocacy groups ($n=20$); and ADHC policy, procedures or guidelines ($n=41$) and associated documents ($n=159$).

Table 1 (see Online Appendix) provides an overview of included sources with a direct or indirect focus on documentation. Most sources ($n=246$, 86%) focussed on documentation directly (peer-reviewed sources $n=11$, grey literature $n=235$), and only 40 (14%) of the sources addressed documentation indirectly (peer-reviewed sources $n=16$, grey literature $n=24$). The online Appendix provides a further summary of the characteristics of the included peer-reviewed (Table 3, online Appendix) and the grey literature sources (Table 4, Online Appendix). In total, 66% of the grey literature ($n=171$) were actual documents used at national, state or ADHC level (e.g. Client Death notification form, see Table 4, online Appendix, G25).

Content themes on information infrastructure in supported accommodation

Seven major thematic categories with sub-categories emerged from the data and were incorporated into a conceptual model (Figure 1) reflecting the current health information infrastructure of people with I/DD living in supported accommodation. The categories were: (i) People, (ii) Documentation, (iii) Communication, (iv) Coordination, (v) Care, (vi) Isolated information systems, and (vii) Gaps between Policy and Practice. The relationship between thematic categories (e.g. 'Documentation') and sub-categories (e.g. 'purpose') is illustrated in the model. 'People' produce 'Documentation' which is often stored within 'Isolated information systems' and used in environments where 'Gaps' exist between 'Policy' ('work-as-imagined') and 'Practice' ('work-as-done'). These gaps and isolated systems affect the 'Communication' and 'Coordination' of information within and across disability and health services and influence the 'Care' of people with I/DD living in supported accommodation.

Insert Figure 1 about here

People. ‘People’ relates to the key agents involved in setting the parameters around the information requirements for persons utilising disability services and those involved in the recording and exchange of such information. People includes the person with I/DD, their family, staff at the disability service (e.g. DSWs, house managers), health services (e.g. GP, allied health, hospital staff), advocacy groups, legislators and policy makers. People have different skill sets and levels of involvement in using documentation in supported accommodation. To illustrate, people with I/DD can be involved in various ways, from ownership of documents (Blair, 2011; Clement & Bigby, 2011; Wahlström, Bergström, & Marttila, 2014) to being excluded from the development of support and health plans (e.g. Commonwealth of Australia, 2015b). DSWs commonly have diverse language and educational and training backgrounds, may have low literacy or limited health literacy, and are often employed on a casual basis that leads to high staff turnover rates (Commonwealth of Australia, 2015b; Iacono, Bigby, Carling-Jenkins, & Torr, 2014; Lennox et al., 2007; Lennox et al., 2013; Riches et al., 2011). All these attributes influence the extent to which disability staff are able to utilise or involve people with I/DD in documentation practices (cf. Davis et al., 2015; Hemsley et al., 2015).

Documents. ‘Documents’ relates to four subcomponents: type and purpose of the recorded information, and its features and storage location as outlined in Table 2 (see Online Appendix).

Communication. ‘Communication’ relates to:

- (i) Sharing of information between people with I/DD, their family and support staff within the supported accommodation; and
- (ii) Information exchange within and across disability and health services.

All documents had the potential to facilitate communication within and across services. Some documents were specifically designed to promote communication, including

hospital support plans (NSW Health & ADHC, 2013), health diaries (Fyffe, McCubbery, & Reid, 2008; Lennox et al., 2012) and hospital passport or communication tools (Blair, 2011, 2013; Luxford et al., 2015). A common theme across sources was that communication plays a central role in the transfer of crucial information (e.g., upon admission (ACI, 2015)).

Furthermore, barriers to successful communication exist if people with I/DD or their carers are not involved in essential health information exchanges (Commonwealth of Australia, 2015b; National People with Disabilities and Carer Council, 2009), or if communication aids or support are lacking or unsuitable (ACI, 2015). A preference for verbal communication coupled with a lack of written records in supported accommodation further complicates the process of communicating health information reliably (Quilliam, 2009). Lack of access to documents relevant to both disability and health services (e.g. missing discharge summaries and/ or guidance for carers) also impacts negatively on care quality and safety (NSW Ombudsman, 2013, 2015; Webber et al., 2010).

Coordination. ‘Coordination’ relates to:

- (i) Integrating information within and across services,
- (ii) Sharing expertise, and
- (iii) Setting up work practices to facilitate effective cooperation of services.

Reflecting the importance of care co-ordination, the ACI (2015) has identified coordination “between health and other service providers (e.g. disability, accommodation) and between different levels and kinds of support within the health system (e.g. primary care, acute care, mental health, justice health)” (p.75) as one of the core issues for establishing “an inclusive integrated health care service for people with intellectual disability” (p.74).

Care. ‘Care’ relates to the model, safety and quality of care provided to people with I/DD living in supported accommodation. All early Ombudsman reports of reviewable deaths discussed the impact of documentation on resident care:

Good documentation of a service user's needs, service responses, regimes and plans are critical to promoting consistent and appropriate care, and it is of significant concern that poor record keeping appears to be prevalent (NSW Ombudsman, 2004, p. 24).

More recent reports have focussed on communication difficulties across health and disability domains and the lack of coordination in managing identified risks (NSW Ombudsman, 2015). Communication and coordination issues between and across disability and health services threaten the pathways of information and thus the continuity of care for people with I/DD living in supported accommodation. Thus, they affect health care actions which rely on relevant information being available (e.g. to implement support plans and specialists' recommendations, or organise follow up care; Hemsley et al., 2015; Lennox et al., 2013).

Poorly integrated information systems / isolated information systems

The sources included in this review reflect that information in supported accommodation is often stored in isolated siloes (Tariq, Georgiou, & Westbrook, 2014) leading to gaps and discontinuities in the quality and safety of care for residents. A lack of clarity about the information held by different services intersecting with supported accommodation can lead to fragmentation or loss of a resident's medical or health history. This can further impact negatively on the person with I/DD's health function, participation, and quality of life, and impede clinical decision making and affect quality and safety of care (Blair, 2013).

Isolated systems - people. Isolated systems are not well-integrated or person-centred and people with I/DD are often unable to access their own information. Consequently, they, if involved at all, are limited to the role of being passive bystanders rather than being actively engaged with their information (WHO, 2015). Information provided by hospitals or specialist health providers is often unavailable or inaccessible to people with I/DD, and to disability

staff with low English literacy or low health literacy who struggle to understand and apply high level definitions, recommendations and guidelines (Davis et al., 2015; Department of Social Services, 2015; Hemsley et al., 2015; NSW Ombudsman, 2016). People with I/DD often rely on their carer to relay their medical histories (Lennox et al., 2007; Lennox et al., 2013).

Isolated systems - storage. Limited access to documentation within and across services also creates isolated information systems. Information transfer is often unreliable with documents not being shared across services or being lost in transit (NSW Ombudsman, 2005). Furthermore, important health documents that are not readily accessible to *all* disability staff may not be used regularly (e.g. daily resident notes being stored on a computer file that is cumbersome to browse instead of an easily accessible book; Quilliam et al., 2014). This impacts negatively on health care and sharing of important health information. Staff in supported accommodation may not realise there is relevant information available (e.g. after discharge from hospital) and health service providers may neither be aware of what information is needed at the residence, nor what care and supports are available at home (NSW Ombudsman, 2013, 2015; Webber et al., 2010).

Isolated systems - documents. Policymakers recognise the problem of isolated information systems in supported accommodation, and have proposed and introduced new overarching policies to *improve* information exchange and deliver integrated and coordinated care. National legislation and strategic reports call on governments to contribute “to improved continuity of care across health services, aged care and disability services to ensure smooth client transitions” (Commonwealth of Australia, 2011; Council of Australian Governments, 2008, p. 4). On a systems level, the NSW Health and ADHC Joint Guideline (2013) aims to improve communication and coordination of information through a cooperatively aligned policy for hospitalisation, including pre-admission planning and shared

discharge summaries. On an individual level, information exchange tools such as hospital passports (Blair, 2011, 2013) or communications strategies (of dementia patients; Luxford et al., 2015) completed by clinicians, carers and families have been implemented. As a consequence of these strategies, the types of documentation required in supported accommodation are increasing in number and complexity. Within the Australian state of Victoria the number of documents contained in the 'Residential Services Practice Manuals' increased by 80% from 1988 to 2009 with the majority being used to monitor quality performance and improve service accountability in case of incidents (McEwen et al., 2014; Quilliam et al., 2015). In the present study, the high percentage (86%) of reviewed sources with a direct focus on documentation, and the large number of practice documents ($n=171$), provides further evidence that information management and recordkeeping for accountability are a high priority for stakeholders in legislation, policy and service provision.

Gaps between policy and practice

Work-as-imagined compared to work-as-done. We found consistent differences between (i) the documentation requirements outlined in legislation and policy related to disability services, and (ii) the manner in which documents are actually used in supported accommodation (McEwen et al., 2014; Quilliam et al., 2015). The gap between policy and practice has been discussed using the concepts work-as-imagined and work-as-done (Hollnagel, Wears, & Braithwaite, 2015). Work-as-imagined refers to policies devised to guide work as it is imagined by policymakers under idealised circumstances, while work-as-done refers to actual dynamic work practices adopted in complex environments (Hollnagel et al., 2015).

The lived experiences of people with I/DD in supported accommodation - as reflected in advocacy reports and journal articles - is different from the idealised view of the world outlined in policy documents. Systemic problems regarding information management include

restrictive access to information and excessive paperwork (National People with Disabilities and Carer Council, 2009). Important policy and care concepts are often reduced to empty slogans, as a South Australian advocacy group outlined in their submission to a senate enquiry:

[We have] heard language like 'person centred thinking' or 'person centred planning' for most of the last three decades- it was individualised service planning before it was person centred planning. We do not see any evidence that [...] disability service providers are actually doing that. (Commonwealth of Australia, 2015b, p. 237)

Impact on work practice and resident care. We found evidence that the gaps between policy and practice can have a negative influence on the work practice and care provided in supported accommodation. Work-as-done on an everyday operational level in supported accommodation relates to the preparation, implementation and quality of documentation related to individual residents, and this reflected problems at a systems level. Reports included in this review reflected that subordinate documents often did not follow overarching guidelines, were not used, or were of dubious quality, and were perceived by staff as administrative paperwork that interfered with other work practices.

Individual plans or health plans for residents were often absent or not revised within the stipulated timeframes (NSW Ombudsman, 2011, 2015). DSWs might have developed support plans or received advice from health professionals but not implemented these plans (Adams, Beadle-Brown, & Mansell, 2006; Dunn, Clare, & Holland, 2010; NSW Ombudsman, 2011). This occurred either because the DSWs lacked specific guidance (Davis et al., 2015), or because they disagreed with the recommendation (Iacono et al., 2014). Incident reports on adverse events were often not submitted or were incomplete, leaving insufficient information for investigations of near miss events to develop targeted preventative measures (NSW Ombudsman, 2006, 2013, 2015). Many tasks related to

documenting health data (e.g., baselines and changes in blood glucose) were treated as a tick-a-box exercise by front line staff who would record but not act on the documented data (NSW Ombudsman, 2006).

Unclear organisational processes led staff to question or refuse to complete some paperwork (e.g. when they felt information was duplicated unnecessarily, Quilliam et al., 2014). The limitations of completing documentation for the purpose of accountability and compliance rather than improving care was also addressed (McEwen et al., 2014, p. 156):

[Forms of] compliance that rely on written evidence can result in a mad rush by service staff to ensure that they catch up with paperwork in the days before an audit[, and are], responsive to neither the needs of the service nor those of people with disabilities.’

Staff also reported being restricted in their everyday care by rigid, regulated planning or policy structures (Hawkins, Redley, & Holland, 2011; Iacono et al., 2014), and documentation was described as creating a high administrative burden, often with little positive yield for the residents (Quilliam et al., 2014) While DSWs viewed residents as a priority (Quilliam et al., 2014), the administrative demands posed by an increasing number of documents also meant that direct support staff could become distracted from their actual responsibilities (e.g. watching residents) sometimes with serious and potentially grave consequences: “For the two [choking] incidents which had occurred out of sight, the staff had been busy with paperwork or attending to another service-user in a separate room.” (Guthrie & Stansfield, 2017, p. 9.)

Discussion

Our review, evidence synthesis, and proposed model has captured the fragmented state of documentation of health information in supported accommodation for people with I/DD. There are several gaps between policy and practices that threatens the quality and

safety of support provided. The NSW Ombudsman's reports repeated concerns about documentation, communication, and coordination and the impact of problems in health information documentation on resident care and safety. Yet, the repeated accounts of poor documentation in the NSW Ombudsman reports also indicates that these issues have not been resolved over time. There have been initiatives aimed at the systems (NSW Health & ADHC, 2013) and individual level (Luxford et al., 2015) to overcome isolated information systems. However, the success of such initiatives hinges on their effective use by all parties involved, and there is little evidence of implementation, peer-reviewed evaluation, or benefit of these strategies in improving communication or co-ordination and care for people with I/DD (Hemsley & Balandin, 2014).

To date, the use of documentation in supported accommodation has received little attention in the disability research literature. Furthermore, there is a lack of robust evidence about how such IT systems can be used beneficially in residential care settings more broadly. Research into documentation in large residential aged care settings has identified links between quality of care and information infrastructure that are similar to those we identified in our evidence synthesis. Evidence from aged care settings shows that information is stored in isolated systems with distinct purposes (e.g. in the aged care facility, or at the hospital or GP), and that information exchange between different care providers is limited, resulting in an uncoordinated service delivery and fragmented care (Georgiou, Marks, Braithwaite, & Westbrook, 2013; Tariq et al., 2014). High staff turnover and support staff characteristics might also impede access to health information (Tariq et al., 2014). Recent research comparing information on residents' medications held in large residential aged care settings and by the residents' GPs showed high rates of discrepancies between both settings that will require regular manual correction and revision for alignment (Makeham & Purdy, 2016). There is no such research comparing accuracy, completeness, or currency of information

sources across multiple health settings (e.g., GP, home, and hospital record) in relation to people with I/DD living in supported accommodation.

The fragmented state of documentation in supported accommodation is problematic and signals a need for a move towards the integration of services and documentation through the implementation of innovative, integrated, and person-centred health information systems. This should serve as a valuable aid to facilitate safe, continuous and good quality care for people with I/DD. To date, most of the IT developments in aged care have centred on the administration of clients rather than their clinical care and there has been insufficient attention to the design and implementation of IT systems to meet the unique aged care environment (Georgiou et al., 2013). To address the unique situation in supported accommodation we propose that it would be helpful to combine conceptual models such as the WHO (2015) model of person-centred and integrated care, and Sittig and Singh's (2010) socio-technical model of health information technology (IT). The findings of this review suggest that having access to health information documents does not mean that DSWs or their managers (i) read or process the information accurately, (ii) are clear on how to act upon the information, or (iii) know how to include the person with I/DD in accessing, understanding, or using the health information to inform their health decisions.

To gain a better understanding of the current information infrastructure, information audits could be conducted to investigate (i) potential discrepancies across sources of information (e.g. held at GP's office versus at home versus at the hospital), (ii) incident reports relating to information errors in supported accommodation, (iii) cost effectiveness analyses on information duplication and information management errors, and (iv) to analyse the language used in person-centred documents for ways to improve guidance and training for healthcare providers in preparation of documents. For people with I/DD, a person-centred e-health solution, such as MyHR could function as a central repository connecting

information silos, and collect data to “identify and address systemic issues” (Department of Social Services, 2015, p. 54). Using MyHR, people with I/DD could store and use their own personal health information and take a more central role in their own healthcare (NSW Health, 2014; WHO, 2015). The patient has rights over information stored in the system, and can view the information at will and decide who else would be able to see the information - further supporting a person-centred approach to health information management (Hemsley et al., 2017).

Limitations and directions for future research

Given that our review focused on the information structures in an environment that is not yet implementing a nationwide electronic health record our findings related to the technical domain are limited (Pearce & Bainbridge, 2014). As noted, we limited the sources to documents found in relation to one state-wide organisation and key national documents. As such, this review might not reflect the health information infrastructure in other states of Australia. Yet, the peer-reviewed literature included in this study reflected that the problems located in the grey literature might also feature in the wider disability sector in Australia and internationally. Future research in the e-health information infrastructure in supported accommodation could explore stakeholder views on PHRs and health information management in supported accommodation. This would help to identify attitudinal and policy barriers and facilitators for improved health information infrastructure in supported accommodation. Furthermore, future research could explore (i) how conceptual models from health services delivery (WHO, 2015) and health IT (Sittig & Singh, 2010) can be combined to provide integrative, person-centred care supported by effective and safe health IT solutions for people with I/DD living in supported accommodation; and (ii) the human right of access to ‘information about me’ at home and elsewhere and how people with a disability could integrate their health information across a variety of paper-based and digital sources,

including PHRs. It is also important to consider how the findings of this review relate to the health information infrastructure for people with I/DD who live in other accommodation settings (e.g. the family home).

Conclusion

Our evidence scan was the first to examine the current information infrastructure for people with I/DD living in supported accommodation in Australia. The evidence synthesis revealed seven themes related to the current information infrastructure: People, Documentation, Communication, Coordination, Care, Isolated Information Sites and Gaps between Policy and Practice. We proposed a model incorporating the interactions between these themes which helped us capture the fragmented state of health information infrastructure in supported accommodation. Our analysis showed that (i) the continuity, safety and quality of care in such settings can be threatened because information in supported accommodation is often stored in isolated siloes, and (ii) gaps exist between existing policy (regulatory documents describing work-as-imagined) and actual practice (work-as-done as evidenced in use of subordinate documents). In cases where policy and practice are not aligned, documentation forms an increasing administrative burden for a thinly stretched and casualised disability support workforce and impacts negatively on the safety and quality of care provided in supported accommodation. If work-as-imagined and work-as-done is to be aligned, the use of documentation may assist addressing systemic problems and deliver best practice care to people with I/DD living in supported accommodation. Any future proposals designed to solve systemic problems in supported accommodation need to take the findings of this review into account, specifically determining if actions taken either exacerbate or resolve the problems reported.

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