Review of FACS Assessment Procedures for Identifying Residents That Need Specialist Nursing Support in Group Homes

Report prepared for:

NSW Department of Family & Community Services (FACs)
Ageing Disability and Home Care (ADHC)

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EXECUTIVE SUMMARY

INTRODUCTION AND BACKGROUND

The United Nations’ Convention on Human Rights for People with Disability (UNCRPD, 2008) to which Australia is bound, protects and promotes the rights of people with disability. Reforms within the disability sector have resulted in a movement away from the “medical model,” towards a more person-centred model. Globally, this is summarised within the International Classification of Functioning, Disability and Health, also known as ICF (WHO, 2001) which broadens the definition of health beyond the medical realm and administered by health care professionals. Thus, in accordance, disability is conceptualised as being a multidimensional experience for the person involved.

Evans (2004) considers medical care still indispensable, and notes that “expert, compassionate care” contributes positively to psychological health. However, the former models tended to place medical experts at the centre of any nursing support. Such an approach, where it remains in existence, is largely inadequate. There is a need to move towards “person-centred” care or “person centredness”; meaning a professional approach that puts the person with a disability at the centre of any treatment or care plan.

People with disability are more likely than the general public to display particular health disparities. Within the community they tend to suffer ill health, have higher prevalence rates of behaviours that challenge, and often have less access to quality health care. The wide-scale transition in Australia (and many other countries) from large residential care units (LRCs) to more individualized housing necessitates a continuing assessment of health support for those with complex and high needs. This means it is important to identify the appropriate assessment tools, and also guidelines that assist in the implementation of any transition into the community, and the impact of ageing and challenging behaviours upon the appropriate level of health care. A change in living arrangement alone will not result in a more person-centred approach.

This report responds to FACS/ADHC’s recognition that for residents who have intellectual disability, complex health, ageing and/or behaviours that challenge, there is a need for skilled staff. Those who require high support for physical or mental health may require staff with nursing skills, the likelihood of which increases as residents age.

BACKGROUND: NEED TO VALIDATE ASSESSMENT PROCESS & TOOLS

Within the LRC environment, all residents receive 24-hour nursing care regardless of need. In contrast, all FACS group homes are operated according to two models only:
- **A nursing led model** operated by FACS Specialist Supported Living (SSL) Services where staff have nursing qualifications or training and work under the Nurses Award and (FACs, 2011; 2013)

- **A general support model** where staff have certificate level training and work under the Community Services Award under which they are designated as Disability Support Workers (hereafter referred to as the DSW model).

FACS does not mix models and is unlikely to do so in the foreseeable future even though government operated services are being progressively transferred to the non-government sector where mixed models can and do operate.

The assessment process that was employed at Metro Residences, the Riverside Centre and Stage 1 Hunter Residences by ADHC involved reviewing residents’ Health Care Plans against the criteria contained in two documents:

- (a) *Framework for Skilling the NSW Disability Workforce* (ADHC, 2010).
- (b) *Health Care Procedures Register* (ADHC, 2012).

An additional “check list” is used to guide these assessments called the *Additional Health Care Needs Assessment Tool* (ADHC, 2012).

A reliable assessment framework is required to assist organisations manage the risks associated with supporting people with complex support needs and/or behaviours of concern. FACs recognizes that the documents do not articulate a list of procedures that can only be administered by nurses. They define procedures that can be undertaken by DSWs who do not hold nursing qualifications, but are trained to undertake these procedures. Procedures that require more advanced clinical expertise not listed in the documents are assessed as requiring immediate access to nursing support (Ryan, internal FACS paper, unpublished, 2017). Consequently, FACS seeks greater clarity on a reasonable and necessary need for nursing support for people in supported accommodation. They also seek objective evaluation of the tools and the assessment processes currently in place.

**AIMS OF THIS PROJECT**

The Centre for Disability Studies was contracted by FACS to:

1. Review the tools/checklist used by ADHC and assess whether this process adequately assesses whether residents require immediate and constant nursing support as part of their supported accommodation.

2. Review a sample of clients who have transitioned to new group homes from LRCs and identify whether clinical procedures outlined in the guidelines/checklists are relevant or sufficiently comprehensive for such assessment

3. Review current literature and consult with other jurisdictions and develop a recommended framework and adjusted suite of tools which are evidence-based,
reliable and valid in assessing whether a person requires constant nursing support as part of their supported accommodation.

**METHOD**

After gaining approval through the University of Sydney Human Research Ethics Committee (HREC), this study included:

- A literature review using a realist or “top-down” approach that provided international examples of best practice.
- Consultation via interviews (in total 22 people) and focus groups (in total 38 people) with a number of stakeholders including the NSW Nurses & Midwives Association; Stockton Hospital Welfare Association; Family and Community Services; Ageing Disability and Home Care (ADHC); 9 staff at Metro Residences and Hunter Residences including RUNMs, NUMs, Directors, Managers and a sample of parents and/or carers of residents in the LRCs who had already transitioned or were awaiting transition.
- Assessment of provided tools
- A review of case files for 9 individuals: 4 from Metro residences and 5 from Hunter Residences Stage 1
- Recommendations for future practice

**LITERATURE KEY FINDINGS: Guiding principles for assessment**

A number of key principles emerged from the literature review (See Appendix 1). These elements were considered foundational to developing and maintaining a robust assessment and support framework, summarized below:

- A person-centred approach
- A framework of human rights
- Focus on Function and Quality of Life:
- Evidence-based assessment

**FEATURES OF GOOD PRACTICE**

- **Quality Health Assessment Tools:** The literature recommends a quality formal assessment tool that covers all health domains. A recent systematic review by Bakker van-Gijsel et al. (2017) examined 20 available health assessment tools for people with an intellectual disability. These instruments were found to vary greatly in design, content, size, and scientific quality. Two were selected as superior to the others in constructing a health assessment for people with ID that meets scientific standards:
1. “Stay well and healthy – Health risk appraisal” or “SWH-HRA” has more than 20 subscales, with good face validity, criterion validity, test–retest reliability, and internal consistency (Hahn & Aronow, 2011).

2. “Comprehensive Health Assessment Programme” or “CHAP” covers the total package of prevention activities and is supported by many GPs. A cluster randomized control trial (RTC) found an increase in health promotion, prevention and new disease detection in the group using the “CHAP” compared to the control group (Lennox et al., 2007).

- **Phased Approach to Assessment**: A number of authors recommended a phased approach to assessment and identification of support needs (NICE, 2015; Leibel et al., 2009; Bakker-van Gijsel et al., 2017) with strong emphasis on early detection, particularly when assessing the need for support related to behaviour that challenges or issues related to ageing.

- **Ongoing, Flexible Assessment Process**: Assessment should be flexible, and ongoing. Regular annual health checks should be conducted for PWD, as there is strong evidence suggesting that health checks are effective at identifying health, behavioural and ageing related issues.

- **Collaboration with Family and Service Providers**: Evidence suggests attending health assessments improves the knowledge and health prevention behaviours of carers and family (Robertson et al., 2014); an important part of the person-centred approach.

- **Explicit Organisational Procedures and Policies**: Organisational structure, clear decision-making frameworks and transparent policies were found to directly impact on the way staff responded to screening, prevention and follow up diagnostic work.

- **Promotion of Preventative Health**: Preventative health measures such as a healthy diet, physical exercise where possible and cognitive/mental exercise are as important for PWD as the general population.

- **Behaviour that Challenges**: The high-quality UK-based guideline (NICE guideline, 2015) includes practical and comprehensive recommendations for practice relating to people with a disability who have behaviour that challenges, and is freely available online with both abbreviated and full versions.

- **Disability and Ageing**: Baseline assessments and screening for dementia are important, and specific tools suitable to people with intellectual disability include The Adaptive Behaviour Dementia Questionnaire (ABDQ), (Prasher, ASIM & Holder, 2004). Health assessments that are specifically geared towards risk assessment for older people should be considered in conjunction with existing broad assessment tools (Leibel et al., 2009).
**KEY FINDINGS: CONSULTATION**

**Two Transition Assessment Processes**

Consultation with key stakeholders revealed two processes involved in transitioning residents from an LRC to the community. One addressed transition needs, while the second process (which is the focus of this report) concerned the assessment of health, behaviour, and age-related needs, designed to allocate people transitioning into one of two government operated models: either a Specialist Supported Living Service (SSL service) staffed by nurses or a group home model staffed by Disability Support Workers (DSWs).

The eligibility criteria for an SSL service includes “the person presents with complex age-related needs or is experiencing the onset of age-related changes; or significant challenging behaviours and/or mental health needs; or multiple health needs that have a cumulative impact on their health and wellbeing”.

The review of current practice identified that despite application of the same assessment framework and assessment tools, there was a disparate experience between the Metro and Hunter Residences. While there was general consensus that the assessment process was effectively applied at Metro Residences, this was not the case for Stage 1 Hunter Residences where validity and reliability issues were raised. All participants in the consultation were able to articulate the steps in the transition process but were less able to articulate how the assessment of health, behaviour and ageing occurred. This indicates a need for written guidelines that: specify the purpose of assessment, clarify roles and responsibilities, and clearly outlines the steps involved in the assessment process required to determine the model of care. A number of conclusions were made that formed the basis for the recommendations.

**KEY FINDINGS: ANALYSIS & EVALUATION OF TOOLS**

The study included a review of current process and the tools / checklist used to assess the support needs of residents relocating from an LRC to a group home, and their effectiveness in determining the level of medical support in the transition of people with disabilities (with focus on complex and high needs, aging, and behaviours of concern). Four tools were supplied with various documentation in order to represent current practice:

- Additional Health Care Needs Assessment tool;
- Audit of Health Status and Health Care Planning; and
- Framework for skilling the NSW Disability Workforce.
- Future Staff Levels Scoping tool / Excel spread sheet

Overall, the multiplicity of documents was confusing and makes it less likely that all are filled in correctly, or read thoroughly. It was also noted in this review that some
information is present in some documents, but missing in others and it is suggested that
information be consolidated into fewer documents.

The Client Risk Management Plan in many instances lists multiple potential risks without
highlighting specific important risks for an individual. In one example, a client’s plan is 13
pages long and includes potential but unlikely risks such as sharps and flammables in a
person who is in a wheelchair. Listing every potential risk means that important risks to life
and safety are buried in this volume of material. For this person, the life threatening risks
are with his malnutrition and aspiration and these are the ones that should be emphasised.
All health conditions related to this person are listed, whether important or not.

CDS has been advised that the Client Risk Management Plan template has been replaced
by My Safety Plan with the introduction of the FACS Good to Great documentation. This is
used in other FACS operated group homes operated by districts. As such, these new
procedures may address the concerns outlined above.

Despite the Specification listing the four tools, the main health assessment tool used within
the Metro client files was the CHAP (2014). The CHAP (or an alternative, validated health
assessment tool) is also used widely in group homes operated by FACS Districts that
support Good to Great. It is noted that the CHAP tool is not used widely in all LRCS such as
Hunter Residences. However, this tool was recommended for all client assessment, and it
was recommended that the CHAP includes:

- a physical activity plan that draws upon the National Physical Activity Guidelines,
  modified according to the impairment/functioning of the individual;
- An epilepsy Management Plan using templates with medications and their dosages
  listed; as available from Epilepsy Society of Australia (e.g. https://www.epilepsy-
  society.org.au/downloads/EMPSeizurex1.doc)
- An asthma management plan with medications and their dosages listed, and that
describes what an asthma attack looks like for that particular person, as with
templates available from National Asthma Council Australia

CASE STUDY EVALUATIVE REPORT

As well as tools/checklists, a sample of client files were reviewed to determine the
application of the assessment process to residents relocating from an LRC for decision to
recommend an SSL or DSW model. Four client files from Metro Residences, and 5 were
reviewed from Hunter Residences (See Appendix 4). Overall, it was clear that it was:

- Variable in how well documents were completed with various errors, omissions and
  incompleted sections, and some not signed off. There were some missing Health
  Action Plans from clients’ records
• Staff need specific instructions and training in each tool including provision of dates and review dates on files

• The Client support needs grid /summary Excel spread sheet lacks definitions e.g. complex health conditions are not defined

• The review of data indicates that at least two persons (Cases A and E) may not have been suitable for a DSW staffed group home due to specific health conditions being unstable and/or risks identified indicating medical vulnerability.

REPORT RECOMMENDATIONS

Rationale: The Need for Guidelines

The need for guidelines is stated within the Framework for Assessing Standards for Practice for registered nurses, enrolled nurses and midwives (2015).

Complex health conditions are currently not defined. It is recommended that FACS develop criteria to define what a complex health condition is, taking into account not only the actual condition, but also its severity and interaction of multiple conditions in the one person. Another consideration is the interaction of multiple health needs of the residents within a group home. Here the threshold for defining complexity may be lower. So, while any individual’s health conditions may not be complex, in the context of living with others who also have health risks, the complexity within the group home increases. This needs to be taken into account when determining staffing structure.

Develop Written Guidelines for the Assessment Process

There is an urgent need for written guidelines that specify the purpose of the assessment of complex health, behaviour and ageing needs and the use of the Client Support Needs spread sheet, as distinct from the transition Compatibility GRID. The guidelines should clarify roles and responsibilities of key stakeholders and clearly outline the steps involved in the assessment process required, and include use of the spread sheet to determine whether the SSL service or DSW model of care is most suitable. These should also include definitions, procedures for handling differences of opinion, procedures for handling changes in conditions and clear criteria and procedures for facilitating facilitate clinical judgment.

Staff Who Know the Person

There is a need to ensure that at minimum one staff member in the assessment process knows the person well and understands their unique communication as well as health care and/or behaviour and ageing support needs. Consultation with clinical staff and use of clinical data is also imperative when assessing complex health needs.
Develop and Apply a Decision Making Framework

A draft decision making framework is proposed for use in cases where clinical judgment is required or where conditions are complex and require further consideration to be able to make an informed decision regarding model of care. A Draft form is provided in the Appendices for consideration:

- Criteria already being used in Metro and the Hunter District covering the factors of intrusiveness/intensity; frequency and sustainability of condition/s and patterns of change.
- Collaborative practice with all key players involved in open dialogue.
- Use of ongoing up to date assessment information that complies with the Good to Great Policy Framework.
- Assessment of level of risk based on likelihood of an incident occurring due to the condition/s and the severity of the consequences of an incident.
- Accountability that identifies who was involved, the final decision, persons responsible and timelines etc.

Consider Using Standard Validated Tool

The “Comprehensive Health Assessment Programme (CHAP)” is used within some ADHC client files, but not all. The CHAP is designed to encourage communication about health care needs between the person with ID, the care provider and their GP to facilitate the coordination of healthcare which in turn supports a more effective assessment process. The support staff complete one part of CHAP and the doctor completes the other. From this assessment process, a Health Care Plan can be developed. It is recommended that this tool in its most recent form be included in all assessments and used as the standard. Not only as it is one of the most comprehensive tools, but as it is also scientifically validated.

Under the Medicare Benefits Schedule (MBS) there are items for health assessments in people with intellectual disability (items 701, 703, 705 and 707). Items to be included in these comprehensive health assessments are listed on the Medicare website (See: http://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&qt=ItemID&q=701#assocNotes). The CHAP encompasses these requirements and in addition provides a more detailed and structured assessment.

Note: CDS recognises that not all GPs are willing to complete the CHAP documentation but the Good to Great manual indicates alternative means by which the documentation can be completed to achieve the same level of information about each individual resident.
**Ongoing Staff Training**

There is need for ongoing basic and advanced staff training for LRC staff regarding the use and recording of health care, behaviour and ageing information for specific assessment tools. File reviews found some existing documents are inconsistently completed and it is recommended staff have training in this area.

There is also need for staff training to work with particular clients who have high and complex needs at the critical time of transition to ensure support needs are correctly and competently met.

**Liaise with PHNs to Ensure Annual GP Health Check**

Ensure that regular health checks are being done before and after people are living in the community. This will be a key strategy – as previously this was not considered necessary by all. However, we know that by doing health checks on people with a disability, this increases the health 'actions' (Byrne et al, 2015). Studies cite evidence around doing an annual GP health check (Leibel et al., 2009, and Bowers et al., 2014). As already discussed, the CHAP is a tool that can be used for these annual health checks.

**Consider Implementing Risk Assessment for Behaviour**

As per the literature review, there should be risk assessments for behaviours that challenge. (See NICE Guideline recommendations; Bakker van-Gijsel et al 2017; Slowie, D., & Martin, G. (2014)). Consider adding a column to the Client Needs Profile to indicate specific and individual risks.

**Specialists Involved in Evaluation of Support Level**

Annual health checks by general practitioners are effective for early identification of health problems, actions such as undertaking preventive health measures and making referrals to relevant specialists for further assessment and/or treatment. There is a case for GPs with knowledge and experience in intellectual disability health to be involved as they are alert to the specific conditions that people with intellectual disability may be at risk of developing. Information from all relevant specialist and practitioners should be taken into account when determining level of support need and consequently model of care.

It is highly recommended that FACS continues to negotiate with the Department of Health to establish regional specialised health services. While in principle people with disabilities should be able to access mainstream medical supports, for people with complex considerations related to health, aging and/or behaviour, specialist health services are
often required - in particular, access to medical and allied health specialists who have experience with intellectual disability. These services support general practitioners in providing health care to this population. The Sydney region currently has some specialised health services for people with intellectual disabilities, including two operated by the Centre for Disability Studies. These services provide comprehensive physical and mental health assessments and recommendations to GPs, other health services, families and disability service providers to co-ordinate high quality care.
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ABBREVIATIONS

AHP – Allied Health Professional
DSW – Disability Support Worker
GP – General Practitioner
ID – Intellectual Disability
NDIA – National Disability Insurance Agency
NDIS – National Disability Insurance Scheme
NICE (Guidelines) – National Institute for Health and Care Excellence
PWD – Persons with Disability
SSL – Specialist Supported Living
INTRODUCTION

In the last decades, reforms within the disability sector have resulted in a movement away from the “medical model,” and towards a more holistic bio-psycho-social model. Globally, this is summarised within the International Classification of Functioning, Disability and Health, also known as ICF (WHO, 2001). The framework broadens a definition of health beyond the medical realm of health as administered by health care professionals. Within it, health is defined as ‘a state of complete physical, mental and social well-being and not merely the absence of disease’ (WHO, 1947). Thus in accordance, disability is conceptualized as being a multidimensional experience for the person involved.

Three important dimensions of “disability” are recognized in ICF: **body structure and function** (and therefore impairment thereof), **activity** (and therefore activity restrictions) and **participation** (and therefore participation restrictions). This classification recognizes the role of various physical and social environmental factors in affecting disability outcomes, as below.

![The Environment, Participation and the ICF](image)

**Figure 1**: ICF bio-psycho-social model of disability

This change in understanding has facilitated a corresponding move towards “person-centred” care or “**person centredness**”; meaning a professional approach that puts the person with disability at the centre of any treatment or care plan.

Evans (2004) notes that medical care is still an indispensable part of disability studies, and that “expert, compassionate care” contributes positively to other areas of a person’s life, such as psychological health. However, one of the key changes (here demonstrated in relation to patients with significant physical disabilities) is that the former models tended to place the medical experts at the centre of any nursing support. Such an approach, where it remains in existence, is largely inadequate.
For health care professionals transitioning to the bio-psycho-social model, Goering (2015) advocates starting with a separation of “disability” from “impairment effects.” This can only be done through listening to (or where more appropriate, observing) a person with disabilities and responding to their needs. She suggests that a conversation be initiated extending from the clinic into public space to recognize the limitations that impairment causes for people with disability. In this way support staff can address health needs but also seek to improve the effects of a person’s impairments on their daily living, even while distinguishing this from a person’s disability. Her second recommendation is to think through the disability/impairment distinction in relation to chronic illness.

Overall, people with disability are more likely than the general public to suffer with ill health. However, people with Intellectual Disability (ID) display particular health disparities (Bakker van Gijssell et al, 2017, 13). They have lower life expectancy and higher morbidity rates. Balogh et al (2016) links this to their difficulty in finding, getting to and paying for healthcare. Iacono (2010) notes that people with an intellectual disability die younger, and have poorer health due to a whole host of factors. They are more likely to experience a range of diseases as they age (e.g. epilepsy, osteoporosis, heart conditions, dementia etc.) and to have impaired functioning (e.g. obesity, visual impairment, diabetes, etc).

When living within the community, people with disability often have less access to quality health care. These access issues are compounded by the fact that they may be less able or unable to communicate their symptoms. As they age, their needs may increase, requiring for higher support in the area of health (Bowers et al, 2014, 261). The NICE guidelines identify that, “people with intellectual disabilities (ID) experience health disparities and are less likely to undergo recommended age and gender specific screening and health promotion. New diagnoses are frequently missed.” Additionally, communication issues cause a significant barrier in the diagnosis and treatment of illnesses that impact upon the quality of life of people with high and complex needs.

Recent prevalence estimates suggest approximately 10–15% of people with intellectual disability present with challenging behaviours (Emerson et al. 2001a; Lowe et al. 2007). The NICE behaviour guidelines agree with this rate of prevalence amongst those with intellectual disability but also note,

...rates are higher in teenagers and people in their early 20s, and in particular settings (for example, 30–40% in hospital settings). People with a learning disability who also have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems (including dementia) may be more likely to develop behaviour that challenges (NICE, 2015).

It is important to recognize that challenging behaviours have been found to significantly increase service costs and further impact upon the individual’s quality of life (Robertson et
In addition, behaviours that challenge have been documented to increase the use of physical and pharmaceutical restraints, and thus a return to institutionalization. These guidelines also highlight the impact of “…care environments that are crowded, unresponsive or unpredictable, those characterised by neglect and abuse, and those where physical health needs and pain go unrecognised or are not managed.”

For these reasons, it is deemed important to identify the appropriate assessment tools, and also guidelines that assist in the implementation of any transition into the community, and in determining the impact of aging and challenging behaviours upon the appropriate level of health care.

1.1 Background: The Devolution of LRCs In NSW

The rights for people with disabilities are entrenched within the United Nations’ Convention on Human Rights for People with Disability (UNCRPD).

- Article 19 directly relates to living independently and being included in the community
- Article 28 determines that their standard of living and social protection must be adequate.
- Article 25 relates directly to health, and the right for a person with a disability to an annual GP health check
- Article 26 describes the right to accessing occupational therapy.
- Article 29 relates to participation in public life
- Article 30 promotes participation in cultural, recreational, leisure and sport.

Other articles include the right to life; equal recognition before the law; access to justice; liberty and security of person; freedom from exploitation, violence and abuse; personal mobility. All Australian governments are now bound by the CRPD. There are various implications for policy and practice in disability services.

The process of deinstitutionalization and moving people in NSW with disabilities into the community has been in progress since the late 1990s. At present, group homes are the most prominent supported accommodation options for people with disabilities. Thus, Hamilton et al (2016) state, “…reflecting international policy, in the last decade in Australia there has been a raft of person-centred government policies supporting individualised funding, self-directed service approaches, and strategies to achieve better social outcomes [Productivity Commission 2011; Australian Institute of Health and Welfare (AIHW) 2011a], and models of supported accommodation (Fisher et al. 2007; Kozma et al. 2009; Mansell & Beadle-Brown 2010). This is beginning to shift with more interest in individualised accommodation approaches (Mansell & Beadle-Brown 2010).”

In 1998 the NSW Government announced a commitment to close all Large Residential Centres (LRCs) with an approach commonly known as ‘devolution’. An LRC is a
facility that provides 24-hour residential support for a large group of people with
disability (more than 20) on one site in a congregate setting. LRCs are funded under the
Disability Services Act (1993; DSA), which was replaced by the NSW Disability Inclusion
Act 2014. In 2012, the NSW Government confirmed its commitment to redeveloping all
LRCs by 2018.

According to the Department of Family and Community Services (FACS) Ageing
Disability and Home Care (ADHC), over the past 10 years more than 550 people who
previously lived in a large residential centre have moved into contemporary
accommodation options across NSW. These options provide a more home-like environment
with more privacy, flexibility in daily living and opportunities for increased participation in
the local community. The redevelopment has involved 18 government and non-government
LRCs across NSW. In Metro Residences alone, between the commencement of the
redevelopment project in 2011 and September 2017 over 285 individuals have
transitioned to the community. Nevertheless, there are presently still several hundreds of
people scheduled for transitioning from Hunter large residential centres to domestic scale
homes in the community.

1.2 Rationale: Need To Validate Assessment Process & Tools

The transition of people with intellectual disability from large residential care units
to more individualized housing necessitates a careful assessment of their health, behaviour
and ageing support due to complex and high needs. Organisations, managers and staff
have obligations under the NSW Work Health and Safety Act 2011 to ensure that people
receiving services in workplaces are safe in so far as that is reasonably practicable. A
reliable assessment framework is required to assist organisations manage the risks
associated with supporting people who require acute or chronic health support needs or
who have significant behaviours of concern that may have a high risk of impacting
harmfully on others or themselves.

Within the LRC environment, all residents receive 24-hour nursing care regardless
of need. In contrast, all FACS group homes are operated according to two models only:

- **A nursing led model** operated by FACS Specialist Supported Living (SSL) Services
  where staff have nursing qualifications or training and work under the Nurses
  Award and (FACs, 2011; 2013)
- **A general support model** where staff have certificate level training in supporting
  people with disability and work under the Community Services Award under which
  they are designated as Disability Support Workers (hereafter referred to as the
  DSW model.)
FACS does not mix models and is unlikely to do so in the foreseeable future even though government operated services are being progressively transferred to the non-government sector where mixed models can and do operate.

The assessment process that was employed at Metro Residences, the Riverside Centre and Stage 1 Hunter Residences by ADHC involved reviewing residents’ Health Care Plans against the criteria contained in two documents:

(c) **Framework for Skilling the NSW Disability Workforce (ADHC, 2010).** This framework is used to assist staff in supporting people’s health care needs. It identifies gaps in the support system, specifically in the skill base of DSWs and provides strategies to bridge the gaps. The framework process includes the Health Care Procedure Register, Health Care Procedures Panel, a Decision-Making Process for procedures to be added to the Register, assessment criteria and a protocol for the Panel members to follow.

(d) **Health Care Procedures Register (ADHC, 2012).** This register outlines health care procedures that can be administered by Disability Support Workers employed under the Community Services Award who do not have formal clinical qualifications. The underlying premise for a procedure to be included on the Register is that it can be performed by staff who, while not having nursing qualifications, can be trained in the procedure. The policy document does not provide an exhaustive list of procedures undertaken by support workers. The original list was compiled from medico-legal advice provided to ADHC on multiple occasions, and were agreed to by the Public Service Association (PSA) and ADHC.

While not its intended use, the framework outlined in these two documents has been used as a “check list” to assist in establishing whether individuals moving to new group homes required constant and immediate access to staff that held nursing qualifications or staff that are supervised by managers with nursing qualifications. An additional “check list” is used to guide these assessments called the **Additional Health Care Needs Assessment Tool (ADHC, 2012).** This was used as part of the assessment process for entry into Summer Hill group homes and had been variously adapted for use by consultation teams working with the Metro Residences and Hunters Residences Redevelopment projects.

FACs recognizes the problem that the documents define procedures that can be undertaken by DSWs who do not hold nursing qualifications, but are trained to undertake these procedures. Procedures that require more advanced clinical expertise not listed in the documents are assessed as requiring immediate access to nursing support (Ryan, 2017.)
Consequently, FACS seeks greater clarity on a reasonable and necessary need for nursing support for people in supported accommodation. They also seek objective evaluation of the tools and the assessment processes currently in place.

Several earlier reports were commissioned by ADHC regarding the assessment of health care and behaviour needs of people with intellectual disability transitioning from ADHC operated LRCs into the community. While these proved informative, results were inconclusive. Mary Ellen Burke was commissioned in 2009 to provide a report in regard to intensive behaviour services. The consultancy was scoped to include refining “principles for the placement of clients with significant challenging behaviour in different supported accommodation models”. While the report made numerous suggestions about what makes a good behaviour support service, it did not provide any strong criteria for whether people might be provided with 24-hour nursing support (Burke, Martin & Tucker, 2009).

In 2011, A/Professor Lynette Lee and Karen Alexanderson were commissioned by ADHC to undertake a detailed study of resident requirements but particularly for nursing support for people living in Metro Residences. In a survey of 236/320 residents, the level of nursing care required for each person was assessed according to: complex medication prescribed; complex processes needed; staff members not confident in their skills and would like more advice; and staff communication difficulties with health practitioner or families. The level of need was “graded” in the following categories:

- Not needed
- Annual involvement of an RN in health planning
- Regular involvement (variously described in the report as monthly or weekly)
- Frequently (more than weekly).

The report concluded that 90% of the people living in Metro residences (212 residents) would be likely to require the involvement of an RN in Health Care Planning and Health promotion implementation, while for more than 50% (124 residents), RN assistance would be required on a regular or frequent basis (Adaptive care systems, 2011).

A later report of the Riverside Centre, Orange concluded that 50% (54 residents of that centre) required 24-hour “nursing care” (Lee, 2012). Lee defined the following clinical characteristics as requiring 24-hour support from qualified nursing staff:

- “PEG feeding;” or
- “unstable respiratory function requiring intervention” due to quadriplegia, or
- frequent seizures or used numerous anticonvulsants for the management due to epilepsy; or
- “severe challenging behaviour that involved violence to self or others that would be unstable “unless a comprehensive management plan is implemented by registered nurses in terms of observation, monitoring and preventive strategies.”
Ryan (2017) concluded that Lee had used a different set of criteria to identify people that required 24-hour nursing care to that being used by ADHC, and that application of this criteria to people in Metro Residences or to the Hunter Residences redevelopment program (Stage One) would likely result in many more people assessed as requiring 24-hour nursing support than occurred. For example, the Health Care Procedures Register and the Framework for Skilling the NSW Disability Workforce would not exclude everyone using PEGs from being supported by non-nursing staff, and that is also likely to be the case for many people with unstable respiratory function or who use multiple anticonvulsants.

2. AIMS OF THIS PROJECT

The Centre for Disability Studies was contracted by FACS to:

- Review the current process and tools/checklist used by ADHC and assess whether the current tools and process adopted by ADHC adequately assess whether residents require immediate and constant nursing support as part of their supported accommodation.
- Review a sample of clients who have transitioned to new group homes from Large Residential Centres and identify whether clinical procedures or health conditions outlined in the guidelines and checklists are relevant or sufficiently comprehensive in making these assessments.
- Review current literature and consult with other jurisdictions and develop a recommended framework and adjusted suite of tools which are evidence based, reliable and valid in assessing whether a person requires constant nursing support as part of their supported accommodation.
3. METHOD

3.1 Ethics Approval

Ethical approval was gained through the University of Sydney Human Research Ethics Committee (HREC) that adheres to the National Statement On Ethical Conduct In Human Research, 2007 (Updated March 2014).

3.2 Literature Review

The framework of realist review methodology (Saul et al. 2013; Pawson et al., 2002) was used to review the relevant literature to inform the project. Alongside the realist review approach, a ‘top-down’ approach was used where more highly synthesised evidence-based resources were sought first as:

1. Initial literature search of databases for primary studies yielded no useful articles and
2. The nature of the information sought lent itself to seeking high quality guidelines and international examples of best practice, rather than primary studies.

Key database searches were performed for three separate domains: behaviour, ageing and health. Inclusion criteria considered articles that were: published between a certain period (2007-current); available in full text; answered or was highly relevant to the aims of the evaluation; provided a high quality guideline or other synthesised evidence-based resource (Straus & Haynes, 2009 pyramid of evidence-based resources); also applicability to the Australian setting was favoured.

3.3 Consultation

Consultation was conducted with the NSW Nurses and Midwives Association and the Stockton Hospital Welfare Association to inform the conduct of the review and to ascertain their views on factors which should be considered when determining whether a person requires constant nursing support as part of their supported accommodation.

Other key stakeholders consulted were identified as Family and Community Services, Ageing Disability and Home Care (ADHC) staff involved in the transition including Directors, Managers and Residential Unit Nurse Managers at Metro Residences and Hunter Residences, as well as a sample of parents and carers of residents in the LRCs who had transitioned and/or were awaiting transition.
A number of questions were drawn from the literature and formed the basis for the focus groups with staff and key stakeholders. (See Appendices). During the consultation phase, representatives were asked for any organisational guidelines or policies that were used for interpreting the findings of the existing assessment tools, and any other relevant documentation or information on the transition, particularly regarding how levels of nursing support were determined.

- **Focus Groups**

A total of five focus groups were held with staff and key stakeholders from Metro and Hunter areas.

**Metro:** One focus group was held with nine staff who were Residential Unit Nurse Managers (RUNMs), Nurse Unit Managers (NUMs) and other key people involved directly with the planning, assessment and transition of residents from Metro Residences into the community 2013-2017.

**Stockton:** One focus group was held with five members of the Stockton Operations Team including the Acting Principal Nurse Manager, an A/Nurse Manager, a Manager, Service Improvement Team and a Senior Project Office.

In addition, three key stakeholder focus groups were also held, one with NSW Nurses and Midwives Association that included a number of NUMs, one with the Stockton Hospital Welfare Association involved families and ex staff, and one with families from the Hunter (representing Stockton, Kanangra, and Tomaree LRCs).

### Table 1: Numbers for Focus Groups

<table>
<thead>
<tr>
<th>Focus Group</th>
<th>Attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Metro Residences RUNMS, NUMS etc</td>
<td>9</td>
</tr>
<tr>
<td>Stockton Centre Operations Team</td>
<td>5</td>
</tr>
<tr>
<td>NSW Nurses and Midwives Association</td>
<td>10</td>
</tr>
<tr>
<td>Stockton Hospital Welfare Association</td>
<td>11</td>
</tr>
<tr>
<td>Families of the Hunter LRCs</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>38</strong></td>
</tr>
</tbody>
</table>

- **Interviews**

Interviews were held with key management from Metro and Hunter, and with a stratified selection of family members who were unable to attend focus groups. Stratification was based on area, and LRC representation.

**Management Interviews:** Individual interviews were also held with ADHC management from both areas. This involved the Metro Residences Consultation Unit (MRCU) Senior Project Officer, Director Large Residential Centres; the Hunter Residences Consultation Unit
Family Members: Interviews were held with family members – some who had gone through a change in accommodation from the large residential centres, and some who were awaiting this transition into the community. A number of families indicated they were unable to attend in person. Consequently, five telephone interviews were conducted with families from Metro and seven from Hunter area – ensuring parents from Stockton, Kanangra and Tomaree were represented.

**Table 2: Numbers for Interviews**

<table>
<thead>
<tr>
<th>Interviews</th>
<th>Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>MRCU Senior Project Officer</td>
<td>1</td>
</tr>
<tr>
<td>Director Large Residential Centres, and a Manager</td>
<td>2</td>
</tr>
<tr>
<td>Medical Officer Stockton</td>
<td>1</td>
</tr>
<tr>
<td>HRCU Senior Project Officer</td>
<td>1</td>
</tr>
<tr>
<td>Stockton Transition Team Project Officer Stage 1</td>
<td>1</td>
</tr>
<tr>
<td>Director Disability FACs, Hunter, Central Coast and one</td>
<td>2</td>
</tr>
<tr>
<td>associate FACs District manager</td>
<td></td>
</tr>
<tr>
<td>Metro RUNM (&amp; NSW Nurses Association Representative)</td>
<td>1</td>
</tr>
<tr>
<td>Director, Contemporary Residential Options</td>
<td>1</td>
</tr>
<tr>
<td>Family Interviews Metro area</td>
<td>5</td>
</tr>
<tr>
<td>Family Interviews Hunter area</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>22</td>
</tr>
</tbody>
</table>

### 3.4 Assessment of Tools and Client Data

A review was conducted of the current assessment process and tools/checklist used to assess the support needs of residents relocating from an LRC to a group home that determine the level of medical support in the transition of people with disabilities (with focus on complex and high needs, aging, and behaviours of concern.

Data relating to a sample of clients who have transitioned to group homes following assessment with the existing tools from Metro and Hunter Residences were also were reviewed in detail in order to assess the tools used in practice, and assist in determining what was possible for nursing staff to determine via such evaluation, with notes supplied. Four client files from Metro residences. An additional five files from Hunter Residences were also reviewed.

Four tools were supplied with various documentation in order to represent current practice:

- Additional Health Care Needs Assessment tool;
• Audit of Health Status and Health Care Planning; and
• Framework for skilling the NSW Disability Workforce.
• Future Staff Levels Scoping tool

Additional reports also reviewed relevant to the assessment process and tools were:

• An intensive behaviour services study (Burke, Martin & Tucker, 2009);
• An audit of health status and healthcare planning in supported accommodation in “Metro Residences” (Adaptive care systems, 2011);
• An audit of Nursing support needs in accommodation support at the Riverside Centre Orange, NSW (Lee/ St Vincent’s Hospital, 2012);
• Assessing Needs for Nursing Report by John Ryan, Director Contemporary Residential Options Ageing, Disability and Home Care Department of Family & Community Services (May, 2017).
4. LITERATURE KEY FINDINGS: PRINCIPLES AND GOOD PRACTICE

A number of key principles emerged from the literature review (See Appendix 1). These elements were considered foundational to developing and maintaining a robust assessment and support framework and are summarized below.

4.1. GUIDING PRINCIPLES FOR ASSESSMENT

- **A person-centred approach** ensures that the person with disability (PWD) is involved and considered central at every stage of an assessment or support. The person and their perceptions, feelings, age, social situation and values should be a priority.

- **The framework of human rights** with particular focus on the rights of people with disabilities outlined in the United Nations Convention on the Rights of Persons with Disabilities should underpin any system developed. Nursing assessments and supports should recognize the autonomy and right to decision-making; and support should be available to facilitate autonomy and decision-making.

- **Focus on Function and Quality of Life**: There is strong consensus in the peer-reviewed literature that any ‘intervention’, be it an assessment of nursing needs or support provided, should have the clear goal of improving the PWD’s quality of life (Bakker-van Gijsel et al., 2017; Troller, 2014; Banks & Bush, 2016; Bowers et al., 2014).

- **Evidence-based**: It is recommended that assessments and supports are based on the best available evidence (Nursing & Midwifery Board paper, Bakker-van Gijsel et al., 2017). In health care, evidence based practice (EBP) is defined as the integration of best research evidence with clinical expertise and patient values (Sackett, Strauss, Richardson, Rosenberg & Haynes, 2000, p.1). Similarly, evidence-based behavioural practice (EBBP) entails making decisions for service delivery or care by integrating best available research evidence with practitioner expertise and other resources and the choices and preferences of those affected.

4.2. FEATURES OF GOOD PRACTICE

**Quality Health Assessment Tools**: A range of health assessment tools exist that can form the basis of a reliable, rigorous nursing needs assessment. Three necessary elements of health assessment tools are: new disease detection, age and gender specific preventative screening, and health promotion. The literature recommends using a quality formal assessment tool (Bakker-van Gijsel et al., 2017) or to use the formal tools as a basis to construct a fit-for-purpose health assessment instrument that covers all health domains. A recent systematic review by Bakker van-Gijsel et al. (2017) examined 20
available health assessment tools for people with an intellectual disability. The Medicare Assessment Form was not included. These assessment instruments were found to vary greatly in design, content, size, and scientific quality. Two particular instruments were selected as of the highest quality potentially and superior to the others as they can be used to construct a health assessment for people with ID that meets scientific standards:

“Stay well and healthy – Health risk appraisal” or “SWH-HRA” consists of more than 20 subscales and has good face validity, criterion validity, test–retest reliability, and internal consistency (Hahn & Aronow, 2011).

“Comprehensive Health Assessment Programme” or “CHAP” covers the total package of prevention activities and a significant number of GPs agreed to use the “CHAP” (Lennox et al., 2006). Moreover, a cluster randomized control trial (RTC) found an increase in health promotion, prevention and new disease detection in the group using the “CHAP” compared to the control group (Lennox et al., 2007).

- **Phased Approach to Assessment:** A number of authors recommended a phased approach to assessment and identification of support needs (NICE, 2015; Leibel et al., 2009; Bakker-van Gijssel et al., 2017) with strong emphasis on early detection. This is particularly important when assessing the need for support related to behaviour that challenges or issues related to ageing. The NICE Guidelines suggest that a risk assessment for behaviour that challenges could form part of a generic health assessment tool. Similarly in the domain of ageing, it is consistently recommended that risk assessment for frailty, falls and dementia are done regularly (Apóstolo et al. 2017, Leibel et al. 2009, NICE guidelines, 2015; Troller, 2014). The phased approach sits well with a structured decision making matrix, as elements of screening for behaviours that challenge and ageing related factors can be incorporated.

- **Ongoing, Flexible Assessment Process:** Assessment should be a flexible, ongoing process (Bakker-van Gijssel et al., 2017; NICE guidelines, 2015; Robertson et al., 2014; Troller, 2014). Regular annual health checks should be conducted for PWD, as there is strong evidence suggesting that health checks are effective at identifying health, behavioural and ageing related issues (Bowers, Webber & Bigby, 2014; Robertson, 2014). This requires strong organisational structures to be in place (Bowers et al., 2014) and close liaison with other health and service providers to be fostered (Leibel et al., 2009).
• **Collaboration with Family and Service Providers:** It is recommended that family/carers and key staff related to the PWD be involved at each stage of the assessment process. Evidence suggests attending health assessments improves the knowledge and health prevention behaviours of carers and family (Robertson et al., 2014), and is an important part of the person-centred approach. It is also recommended that strong links be established with other local health and service providers, and that these links are formalised in some way (Balough et al., 2016).

• **Explicit Organisational Procedures and Policies:** Organisational structure, clear decision-making frameworks and transparent policies were found to directly impact on the way staff responded to screening, prevention and follow up diagnostic work (Bowers et al., 2014). Importantly, this requires attention be given to evaluation measures, collaboration, documentation and staff training.

• **Promotion of Preventative Health:** Preventative health measures such as a healthy diet, physical exercise where possible and cognitive/mental exercise are as important for PWD as the general population (Troller, 2014). Involvement of the PWD along with their family/carers and key staff in the assessment and support process is key.

• **Behaviour that Challenges:** The high quality UK-based guideline (NICE guideline, 2015) includes practical and comprehensive recommendations for practice relating to people with a disability who have behaviour that challenges. The guideline is freely available online with both abbreviated and full versions. Specific factors to include in an initial assessment of behaviour that challenges are found in NICE 8.5.2 & 8.5.5 (p. 168 of full guideline) and are summarized in this report.

• **Disability and Ageing:** Various health problems and disability specific problems are often dismissed by staff and family as ‘just getting older’ (Bowers et al., 2014; Troller, 2014), and may include physical decline such as worsening mobility or toileting and also changes in cognitive functioning and dementia related needs. Dementia amongst PWD is thought to be under-diagnosed (Bowers et al., 2014; Troller, 2014), while people with Down syndrome are at increased risk of developing Alzheimer’s disease at a younger age than others in the population. Baseline assessments and screening for dementia are therefore important, and specific tools suitable to people with intellectual disability include The Adaptive Behaviour Dementia Questionnaire (ABDQ), (Prasher, ASIM & Holder, 2004). Health assessments that are specifically geared towards risk assessment for older people should be considered in conjunction with existing broad assessment tools (Leibel et al., 2009).
5. ADHC ASSESSMENT PROCESS

5.1 Two Transition Assessment Processes

Consultation with key stakeholders revealed two processes of transitioning residents from an LRC to the community. One process addresses the transition needs related to geographic location; person-centred choices for the person with disability and their family; and compatibility with other residents and transitional arrangements. This process is managed by the Contemporary Residential Options team. This transition process was not deemed to be the focus of this inquiry. The second process (which is the focus of this report) concerns the assessment of health, behaviour and age-related needs and was designed for allocating people in transition to one of two government operated models: either a Specialist Supported Living Service (SSL service) staffed by nurses or a model staff by Disability Support Workers (DSW model).

The target group for SSL services, according to the eligibility and access Guidelines (FACS 2013, p.5) comprises people with an intellectual disability and complex support needs relating to ageing, behaviour and/or health who require:

- Supported accommodation in an intensive environment with clinical nursing support, but whose needs cannot be met in their current home or service setting or
- Respite service
- Planned therapeutic placement.

Eligibility criteria for an SSL service #3 states “the person presents with complex age-related needs or is experiencing the onset of age-related changes; or significant challenging behaviours and/or mental health needs; or multiple health needs that have a cumulative impact on their health and wellbeing”. Assessments for eligibility to an SSL service are completed by clinical support staff, such as Registered Nurses (RNs), and Registered Nurse Unit Managers (RUNMs).

An additional clause in the eligibility criteria states “individuals who have substantially complex needs and who are living in an LRC that is undergoing redevelopment may also be considered for entry into SSL service on the basis of friendship groupings and intimate relationships” (FACS 2013, p.5).

From the focus groups and interviews conducted, it became clear that apart from these eligibility and access criteria and brief guidelines, there were no other written clinical guidelines used to determine the allocation of residents to either model.
In practice, evidence from data, interviews and focus groups was that various rationales were used for the allocation of individuals to an SSL service or a DSW model, and that the two assessment processes involving both transition goals and transition needs as well as the assessment of health care, behaviour and ageing related needs often occurred simultaneously and impacted upon one another.

5.2 The health care, behaviour and ageing assessment process

The prescribed process for assessing whether individuals require constant support by specialist nursing staff or whether their needs can be met by trained disability support staff was outlined by FACs personnel as follows:

The CRO team would use available resident records to pre-populate a template within an Excel Spreadsheet that listed the likely members of a group home household and their requirements against various health-need domains.

The first column contained a short “dot point” summary of the person’s major health conditions and relevant impairments. Fifteen other columns invited a yes/no response against a number of possible clinical requirements staff might be required to administer. The list of requirements are clinical procedures that are usually only undertaken by Nurses because they are not listed as tasks that could be undertaken by appropriately trained Disability Support Workers as outlined in the Framework for Skilling the Disability Workforce and Health Care Needs Register. The items listed are:

- Complex health conditions (N.B. Not defined)
- Polypharmacy (using 5 or more medications)
- Injections (short for subcutaneous injections)
- Oxygen therapy
- Requires suction
- Ventolin
- Wound care
- Catheterisation
- Bladder irrigation
- PEG insertion
- Mental health
- Restricted practices
- May require restraint
- Previous unsuccessful community placement
- Meets SSL guidelines

The prepopulated spreadsheet was then used to facilitate discussion in a meeting hosted by CRO staff with clinical support staff such as Registered Nurses, and Registered Nurse Unit Managers (RUNMs). The accuracy of the spreadsheet was checked and updated “live” using a lap-top computer from data contained in what is commonly referred to as
“the person’s Green File”. The Green file is a collection of documents that included relevant health care information such as:

- Health care plans,
- Lifestyle Plans (LS)
- Behaviour Support Plans (BSP)
- My safety plan
- Client risk profiles 1 and 2
- Person centred tools such as important to and important for

The spreadsheet also details likely staffing requirements, staff training that might be required and the names of the staff attending the meeting/s and making the assessment. The same basic process was followed at Metro Residences and Hunter Residences.

5.3 Determining A DSW or Nursing Model: Metro

On the whole the Metro staff and families consulted expressed satisfaction about the assessment and transition processes, and the resulting improved quality of life for the residents. It became clear during the consultation process that respondents reported on both transition and assessment matters as a combined process, that transition issues tended to dominate, and that the memory of staff and families regarding the steps undertaken for assessment was at times incomplete. Staff were clear that an RN who knew person best initially gathered information and developed a profile for each resident that was accurate and up to date. A consultation process with families and relevant others followed including RUNMs, relevant medical and/or behavioural staff etc., and this collaborative practice developed trust between parties. However, family members spoke more about the transition process and indicated they had been minimally involved in the health assessments but trusted nursing staff to complete the clinical assessments and make informed decisions based on these assessments.

Metro focus group members confirmed that determining the appropriate model (SSL or DSW) was based on assessment data structured around three domains; complex health, ageing and behavioural issues. Considerations for determining the need for a complex health (SSL) model involved consideration of data summarised on an Excel spreadsheet, and application of the Health Care Procedures Register as per the prescribed process. However, substantial consultation and application of clinical judgment around complex issues was also required. Various meetings were held with key RUNM’s for further verification of complex conditions and treatments, as well as category of staff responsible for the task attached to that condition e.g. Registered Nurse, Endorsed Enrolled Nurse, and Assistant in Nursing. Additional considerations for complex conditions and areas of concern where an SSL service was in question mentioned included:
• Complexity of health needs: a single condition or a combination of health and/or other considerations, but particularly if the person was fragile or unstable;
• Areas/topics of particular concern or risk (e.g. swallowing, need for injections etc.) led to further analysis of data from the Annual Medical Review, Eating & Drinking Plans, Health Care Plans (e.g. Epilepsy Management Plan, Diabetes Management Plan, Health Care Summary Plan and Client Risk Profiles);
• Time required (duration of each task was calculated);
• Frequency and continuity of support required (e.g. once per week versus twice per day);
• Intrusiveness of support need;
• Disagreements between parties had to be discussed and resolved;
• Consideration was given to an individual’s relationships made through long term residency in a particular unit, or strong family desire to have their loved one live with the people they knew;
• Complexities with particular conditions such as diabetes. People who required insulin injections were deemed to require SSL nursing support but in some cases, they could be managed in the DSW model because treatment was changed from oral medication to injection and the individual was stabilized before being transitioned out.

In all cases a Clinical Nurse Consultant provided input, the RUNMs involved had firsthand knowledge of the individual and there was clear input given by the GP and various specialists (care notes etc.) such that all information was taken into account when choosing the model of care before sign off.

Table 3: Summary of key health care considerations resulting in SSL service

<table>
<thead>
<tr>
<th>Condition</th>
<th>Reasons why SSL service required Metro</th>
</tr>
</thead>
</table>
| Dysphagia                        | • 56 of the identified clients had Dysphagia increasing their risk of aspiration pneumonia and chronic chest infections  
• 10 fed enterally  
• Additional complex eating and drinking plans and detailed meal time management components that required an RN. |
| Epilepsy                         | • 45 clients – prolonged seizures which required the administration of PRN medication and Oxygen |
| Muscular skeletal conditions     | • RN required to demonstrate clinical alertness  
• Forty clients required repositioning up to 15 times per day to ensure correct positioning for feeding, maintaining good skin integrity, administering bowel medications, supporting Areas of Daily Living (ADL), and  
• 18 clients - minimizing the symptoms of Gastrointestinal disorders |
| Medication                       | • Some clients required administration of medication orally or enterally undertaken by an RN or EEN at a minimum of twice daily |
By early September 2017, 285 people had been transitioned to ADHC District and NGO models from metro residences, with 160 or 56% assessed as requiring a DSW model and 44% a nursing model. Also 53 people from Metro had passed away. Table 4 provides a more detailed breakdown according to model and government or NGO provider.

Table 4: Numbers assessed for Metro Residences per model and provider

<table>
<thead>
<tr>
<th></th>
<th>DSW Model</th>
<th>SSL/Nursing model</th>
</tr>
</thead>
<tbody>
<tr>
<td>NGO DSW</td>
<td>75</td>
<td>NGOS Nursing</td>
</tr>
<tr>
<td>Western Sydney District: DSW</td>
<td>70</td>
<td>LRCSSL Nursing *</td>
</tr>
<tr>
<td>Northern Sydney District: DSW</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Total number</td>
<td>160</td>
<td>125</td>
</tr>
<tr>
<td>Percent</td>
<td>56.1%</td>
<td>43.9%</td>
</tr>
</tbody>
</table>

*plus 19 vacancies

There was unanimous agreement that the ultimate decision regarding the chosen model of care was a collaborative sign off between CRO, RUNM and family. This aligns with and is an example of the use of an evidence based practice (collaboration) as identified within the review of literature for the project.

5.4 Minimising Behaviours of Concern Metro

The RUNMs emphasized that behaviours of concern are not static, but change. If a client profile included historical behaviour problems, staff recognized that this may have changed due to age and/or good management control – or, behaviour could still be a risk. Therefore, current data was checked to ensure that historical tags and labels did not dictate where people went.

The importance of a person who knew the resident well was noted as critical to decoding the information within reports. This involved determining if a certain incident was one off, or a sign that the behaviours were continuing or escalating. It was recognized that

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1 Data provided in correspondence by Metro Residences Department of Family and Community Services Contemporary Residential Options, 12 September, 2017.
transition or change itself could trigger behavioural incidents, as assessing anxiety status and ability to cope with change was crucial for some. Assessment information in these cases often had implications for the transition process and requirements.

There was recognition that behaviour of concern does not require a nurse per se, but rather trained and skilled staff who can work with the person and their behaviour effectively. A number of services related to behaviour that were previously provided at Metro LRC by nurses are now supported by DSWs but also involve information being collected and external services supplied by Behaviour Support Specialists.

### 5.5 Ageing and Health Concerns Metro

Various concerns were identified as assisting in the allocation of residents to the SSL service due to Ageing and Complex Health:

- If someone’s health deteriorated, the RUNM would ring the CRO team and trigger review – which could result in a change in model if necessary to better meet needs.
- If needs changed, families were also consulted regarding the best model, implications for location etc.
- The fragility of the residents was assessed on a regular basis prior to transition.
- When it was unclear whether the aged care or the challenging behaviours should be prioritized, staff worked with individual cases to determine the higher level of need – the final decision had to be a clinical one.

### 5.6 Determining A DSW or Nursing Model: Hunter

The redevelopment of Hunter LRCs has been complex and vexed. Residents have complex health care and/or behavioural support needs, with ages ranging upward of 60 years. These factors contributed to the contention over the model of care required, with many families and staff advocating for fulltime nursing care (SSL model) as occurs in the LRC setting, regardless of level and intensity of support need, due to risk management concerns. Industrial issues (work bans) affected record-keeping and there was a lack of written guidelines and therefore confusion in the decision-making processes.

Stockton Hospital Welfare Association members highlighted their concerns for the high and complex medical needs of this population, coupled with the current and foreseeable difficulties of clients accessing informed and competent community resources and specialised services under both DSW and SSL models in the longer term. The LRC currently enables the provision of a nurse familiar with complex health issues to be on the floor at all times, and this was seen as significant in often serving to prevent crises, and
facilitating risk management. It was unclear to them how specialized health care would be delivered in the longer term.

Furthermore, with redevelopment having been prolonged it spans a significant time of change and anxiety for families and staff, with the Hunter region being one of the trial sites for the National Disability Insurance Scheme (NDIS). Families were involved in NDIS planning, and this coincided both with the LRCs being transitioned to the community and news of the closure of ADHC in 2017-18. All services are now being transferred to the non-government sector. Additionally, the Minister announced to families that people could live anywhere in the state of NSW, and as some families live remotely and desired their family member closer, the relocation area is extended from one house in Albury, through to two houses at Tweed Heads on the Queensland border.

In Stage 1, a total of 51 clients were transitioned from Stockton LRC to 11 group homes. Three homes with twelve clients were transitioned to an NGO and 8 homes with 39 clients were under the auspice of Stockton LRC. All of these homes operate under the Disability Support Worker (DSW) or group home model. All these homes have now transitioned to Hunter District Management. There were an additional three units already in operation before Stage 1 and under Stockton remit classified as SSLs. These three units have also transferred to Hunter District.

According staff and families, the majority of the 51 client transitions were successful, but especially for nine of the group homes involved, despite initial anxiety about the move. The feedback includes that quality of life of residents has improved and a number of clients have experienced positive behavioural changes. Additionally, several representatives of the NSW Nurses and Midwives Association focus group also reported they knew and are associated with houses in Hunter that are successful, as experienced nursing staff have moved out and are successfully managing issues (although not working as nursing staff). This included one house where residents had high complex behaviour.

Nevertheless, the deaths of two individuals and hospitalization of several others from one house raised critical questions about the transition process and the decision making process around the model of care required.

5.7 Assessment Challenges Hunter

There appeared to be general acceptance that The Framework for Skilling the NSW Disability Workforce, and the Health Care Procedures Register were sound in guiding decisions about procedures that could be performed by trained DSWs. However, CDS received a substantial amount of feedback in the Hunter about the assessment process itself and difficulties encountered in practice.
However, RUNMs from the Stockton Operations Team and representatives from the NSW Nurses and Midwives Association raised a number of concerns about the assessment data used and its interpretation. There was confusion and some disagreement over who made what decisions, the roles and responsibilities of the various stakeholders, and there was lack of clarity of the steps in the assessment and decision making processes.

- **Differing assessment tools:** Respondents were aware data were recorded on a spreadsheet that was used for matching compatibility and presumably, determination of the model of care, although many people consulted were unclear how decisions occurred. Most respondents including RNs and RUNMs simply talked about “the GRID.” CDS was supplied a copy of an Excel spreadsheet from the Metro CRO summarizing 15 key physical health, mental health and behaviour areas. This largely recorded information in a yes/no assessment. A similar version of this document entitled *Identifying Client Support Needs* was also supplied to the CDS team for one household. However, late in the project it became evident that an additional spreadsheet entitled *Client Commonality Grid* was also employed in the Hunter. This GRID summarizes 19 domains (including disability, health and medical, current residence, hobbies and interests, independent living skills, communication, diet and eating, historical behaviour, behaviour requiring support etc.). None of the respondents (staff or family) indicated awareness of two spreadsheets, and it is unclear which spreadsheet people referred to when discussing the assessment process – which thus suggests confusion related to the *Client Commonality GRID*. Meetings facilitated by the CRO team apparently addressed both processes of transition as well as the assessment of health behaviour and ageing assessment, and most nursing staff were of the opinion that meetings were more about compatibility rather than health or behavioural support. They were clearly able to articulate the transition process but were unclear on steps in the assessment process.

- **Purpose of the GRID:** Staff representatives stated the assessment grid was considered a paper matching tool that covered likes/dislikes, commonalities with people, and assessed who was suitable to live with whom. It was viewed as a lengthy process involving consent that was used primarily to guide the mix of residents based on strengths and strong friendships etc. The GRID does also summarise health and behavioural support needs so it is not surprising staff confused the two.

- **Limited Collaboration:** RUNMs from the Stockton Operations Team and representatives from the NSW Nurses and Midwives Association raised concerns around use of the assessment data recorded on the spreadsheet or GRID. There
was confusion over who made what decisions, the roles of the various parties, and
a lack of clarity (and even some disagreement) on interpretation of data used for
decision-making regarding the model of care. LRC staff felt predetermined
decisions were made and presented to them, with all clients allocated to the DSW
model and no nursing models approved or open for negotiation. Staff from the
NSW Nurses Association also stated they were informed the DSW model was
chosen and houses built for an ageing in place model with anticipation things can
change. Lack of trust, limited collaboration and lack of negotiation at that time
negatively impacted on the decision making process.

CRO staff reported that as formal meetings to facilitate the assessments were not
well attended, most negotiations between the CRO team, RUNMs and other staff
were informal. Several RUNMs stated that although they attended meetings, they
were not always clear on the purpose of the meeting, and were uncertain of their
roles and responsibilities. No written guidelines were available and only after
Stage 1 was complete were clinical staff aware that clinical decisions were their
responsibility.

- **Lack of consensus methods:** In Metro, the CRO leader ensured that RUNMs filled
in the medical conditions and health care needs on Client Support Needs spread
sheet, and consensus building methods were used. Stockton Operations team
members who were clinical staff claimed the spread sheet was completed by the
CRO team from assessments and data recorded on file, and results were
presented to RUNMs who were asked to simply tick if nursing supports were
required or not for certain procedures e.g. oxygen, IMI injections, etc. There was
lack of clarity around processes for reaching agreement on health care assessment
and no clear process for dispute handling. Some RUNMs stated they felt powerless
and although disagreeing with assessments, some stayed quiet while others simply
refused to sign off on assessments. There were no written guidelines to improve
clarity, or provide guidance in cases where clinical judgment was required for
decision-making regarding the model of care.

- **Validity and Reliability of Assessment Data:** The reliability and validity of the
assessment process was questioned because of lack of collaboration; differences
of interpretation in assessment data; and limited participation and involvement in
assessments by some key players. Lack of clinical input in some cases was also
reported, including the absence of clinical input from some specialists.

LRC staff and representatives from the NSW Nurses and Midwives Association
acknowledged that rolling industrial work bans over several years had meant that
relevant clinical data were recorded in client files but using older assessment forms instead of current ADHC Good to Great forms and assessment plans.

**Missing dates in documentation:** Neither the Client Support Needs spreadsheet not the Compatibility Grid supplied to the CDS team have dates recorded, so it is unclear when assessments were completed. Lack of dating means it is not possible to determine whether assessments are current or out of date.

- **Complex health issues:** There was criticism among nurses that the spreadsheet (GRID) did not accurately reflect the complexity of health conditions. This was possibly related to the fact there was lack of understanding that the spreadsheet was a summary and further discussions could and should be triggered by data contained within it. There do not appear to be any written guidelines that explain the purpose of the spreadsheet and how these should be completed and used and the presence of such may have alleviated some of these problems.

- **Complex health support needs:** Nurses stated that for the health checklists used, there was no way to differentiate the degree of support required when recorded on the summary grid e.g. epilepsy may be stated, but severity was not indicated e.g. number or severity of seizures. Some RUNMs felt their views were not respected or listened to, some refused to sign off on data, and one person stated that additions made by hand during the meeting were later found missing on the computer version.

- **Mental health support needs:** There was concern the assessment process and tools used did not capture mental health conditions such as anxiety and depression that can manifest as behaviour, as these assessments need skilled /knowledgeable staff to interpret and manage symptoms correctly. Guidelines are required to improve understanding of the assessment process being a collaborative, flexible process that can accommodate such concerns.

- **Risk of sudden changes:** Medical conditions for some people were at risk of worsening quickly; particularly people who are nonverbal or have limited communication skills. Examples cited included: swallowing problems that can rapidly develop into aspiration pneumonia; episodic conditions that need an RN or red alert for immediate care; idiosyncratic patterns or the meaning of certain changes in behaviour. In one case, a “quiet episode” was the only indicator of a twisted bowel in a client who has a high threshold for pain and/or inability to communicate pain. Such risks could no doubt be accommodated in the assessment process, as individual communication patterns and risk factors could and should be identified in assessment files. They could possibly be summarized on the Client
Support Needs spread sheet in an additional column. Or they could be summarized on the Client Commonality Grid under the columns “issues” and “solutions.” The fact this issue was raised and seemingly not addressed in some instances, reinforces the need for written guidelines as well as open communication and ongoing consultation between all stakeholders involved in the assessment process. **FACS has advised** CDS that the some of these gaps are addressed in the Health Planning procedures and tools made available under the Good to Great Planning Framework which has been widely used in other ADHC group homes but not so widely in LRCs.

- **Good management of current issues:** There was concern about how well assessments accounted for type and level of support required and provided to ensure conditions or behaviours remained stable due to good management. This point indicates staff did not trust and were not confident how assessment data were being interpreted, or that they had opportunity to explain and advocate for level of supports needed. The need for written guidelines and collaboration again appears to be key.

- **Recognising changes to Assessment Data:** Representatives from several of the focus groups expressed concern over there being no known process to monitor changes to assessment data over time, or to have input to change the model of care required due to changing health needs over time due to ageing and /or ill health. Recognition was given to difficulties doing assessments and planning six or more months out from transition, yet medical conditions can change suddenly or slowly and either increase or decrease support needs e.g. dysphasia. It was suggested there should be a red flag alert system in place that is triggered if and when changes occur in health or behaviour over time, with open discussion and joint decision making. The CRO leader stated it was the responsibility of LRC staff to advise if and when any status changed. However, LRC staff appeared unaware of this fact, and in contrast, stated they felt powerless in the process. This was in contrast to Metro residences where RUNMs stated they attended numerous meetings to ensure assessment data were correct and up to date, especially as the actual move became imminent.

- **Need for objective guidelines:** An unintended consequence of the two deaths (raised in one of the focus groups) is the tendency some LRC staff now have to be overly cautious in providing assessment estimates, with the inclination to over correct and overestimate risk in areas such as risk of dehydration. This response highlights the subjective nature of some assessments and the need for more objective guidelines.
Overall, the assessment process was marred, due to poor and/or limited communication and a lack of trust between parties, which negatively impacted the clinical inputs. The lack of written guidelines around the assessment process, its purpose, and the roles and responsibilities of staff is clear. As a result, there was limited collaborative sharing of critical assessment information. These problems affected the validity and reliability of the assessment data and the way data were interpreted.

### 5.8 District criteria for SSL model of care

In an interview with the Director, Disability Hunter, information was provided about the criteria and process used at the district level for skilling the disability workforce and as a first indicator when assessing when an SSL service that requires a nurse (RN or AIN) on a daily basis rather than a group home staffed by DSWs may be required. Similar to Metro Residences, criteria used addressed: if and when procedures are intrusive and/or continuous; and if procedures are sustainable in the long term in a DSW setting or require a more specialized setting to meet unique health, behaviour and/or ageing support needs. Specific criteria applied and discussed collaboratively were identified as follows:

- **Intrusiveness:** involves any procedures that are invasive. That is, a procedure involving something going into the body, such as regular medication or treatment e.g. injections, oxygen regulated and charted.

- **Continuous:** means regular twice or three times a day such as injections. A DSW cannot give injections, although if a client has diabetes they can do skin prick monitoring (which is not invasive).

- **Sustainable:** involves evaluating whether DSW staff can continue to provide the level of intensity and/or frequency of support required by a person in a five bed group home setting on an ongoing basis, or if more constant and individual one-on-one support is required that cannot be sustainably carried out in the group setting, over and above compatibility issues.

A number of key considerations were identified that assisted in the application of clinical judgment and the decision making process:

- **Up-to-date and accurate assessment information** was identified as a critical component for achieving the best decision about the right supports and who can best provide appropriate support, under either a DSW model or SSL service/nurses role.

- **Guidelines** that identify nurse and DSW roles and procedures were considered clear. Examples cited in support included that DSWs understand the limitations of their role; including that they cannot do deep throat suctioning or administer morphine for palliative care.
• **Mapping the staff roster around the client map of supports and routines:** This is done under both models (SSL and DSW) at the District level, especially as a client’s needs change, and was considered critical for managing several clients in a group home setting with different needs.

• **Medication:** DSWs do not draw up the medications, but medication can be given correctly under the DSW model as this can usually be managed through Webster packs. Staff training is imperative, as DSWs are taught to pack correctly using colour codes and numbers, double check for accuracy, administer the medication and chart correctly using the appropriate medication paperwork.

• **Behaviour of concern** does not require invasive procedures and consequently does not require nursing staff, although DSWs do require staff training and skill to manage behaviour of concern. The district experience is that there are lots of complex behaviour units all manned by trained DSW staff who also engage with relevant specialists in the community.

• **Dual diagnosis:** Many clients who have intellectual disability and mental health care needs can be well managed under the DSW model. This requires Positive Behaviour Support (PBS) to be put in place, ABC data recorded and interpreted, as well as engagement of DSWs supporting the client with relevant health professionals (GP and psychiatrist to evaluate needs). Episodic conditions are managed by calling the mental health care team or Triple 0 who do their assessment and when the person is stable they can be returned to the care of the DSW. Staff require information about what to do, staff training around how and when to access community facilities and families are always informed.

• **Data for change** are used in the DSW model to monitor when changes may result in the need to change the support model for a person based on a change in health and medical support needs, mental health and ageing:
  - Dementia/ageing monitoring relies on specialist gerontologists and the aged care assessment process. Staff must keep baseline data and work with specialists for regular reviews about what supports to put in place. Staff can order in specialized equipment. Key flags are if a DSW assesses that a client needs increased medical or specialist treatment due to increased age related falls or risk of falls, behaviour changes (Alzheimer’s); increased incident reports, too many work and safety issues, increased visits to GPs; increased hospitalisations e.g. continual bouts of aspiration pneumonia in clients with enteral feeds. A GP may make the call to say when it is time for a client to move to the next stage of care. These are also the same flags that can and should be used when determining the model of care when transitioning from the LRC.
o Oxygen therapy being required is an immediate red flag for nursing care.

o A high pattern of need or a pattern of changes is usually picked up by the team or DSW staff and triggers investigation e.g. increased incidents, increased GP visits, or staff making comments such as “I can’t manage any more”. Such patterns trigger the client being reviewed by the manager to consider placement options, involving the extended network.

o Each plan is reviewed quarterly – or more often if there are changes. More frequent reviews being needed may also signal a need for a change in model. Complex client reviews need additional supports with input from all major specialists and professionals in the person’s life that are involved such as GPs specialists, Allied Health etc.

o When queries arise as the reason behind symptomatology e.g. pain can be medical or behavioural. If in doubt, functional and health assessments should be done, looking outside behaviours and symptoms. Under the DSW model, staff are continually watching, taking data, having regular discussions with the GP etc.

The final assessment for an individual to move from a District (DSW) group home to an SSL (nurse led) model is made by a Panel consisting of clinicians and staff including the senior manager, coordinator from the group home, Team leader and depending on the client, a CNC etc., and an independent representative (external). Hence there are representatives from all areas to ensure all aspects are covered. The whole panel agrees with the decision the Proposal is written up and if required, a transition plan developed. The proposal is then sent up to the Director to endorse.

5.9 Hunter Residences Group home

A sample of client files were reviewed to determine the effectiveness and application of the assessment process and tools/checklist used to assess the support needs of residents relocating from an LRC to either an SSL or DSW model. Five client files were reviewed from Hunter Residences in order to assess the tools used in practice, and assist in determining what was possible for nursing staff to determine via such evaluation.

This was in the context of some contention existing over whether residents from Stockton would have been better served in an SSL model rather than a DSW model, because of the complexity of support needs of many of the individuals involved. The problems arising served to heighten tension and highlight the confusion over roles and responsibilities and lack of guidelines and clarity in the decision-making process.

The assessment of one Hunter group home especially was fraught. It was assessed as not requiring an SSL model of care, as the expertise of nurses was not required to address the
clinical needs of any of the individuals living in the home. However, grouping of a number of people together, all of whom had complex support needs that included 1:1 support at mealtimes might have changed the overall assessment result because of the difficulty and stress for staff having to manage so many people with complex needs all at once.

During the consultation, various participants discussed the option of an increased range of models of care being required, over and above a straight SSL or DSW model. Such a move is commended and may have been useful for a situation like the Group Home where even part-time nursing staff may have been helpful. It is recognized this is not an option for ADHC but is relevant in the NGO sector where greater flexibility in models of operation is already occurring, and may be pertinent for some of the clients yet to transition in the Hunter in 2018-2020.

Future discussions about other options are being considered at the district level with possible future plans to work towards a blended model, where one or more RNs could support DSWs across houses. A number of major issues need to be resolved to adopt such a model, including the fact staff are employed under different awards and conditions (a nurses award and a DSW award), and a blended model would need a structure including a reporting structure.

5.10 Other influences on the assessment process

The Framework for Skilling the NSW Disability Workforce, the Health Care Procedures Register and the process for determining those procedures that can be carried out by DSWs with relevant training appeared clear and widely accepted.

However, this was not so for the process required to ensure the assessment data used for these decisions was valid and reliable. There can be numerous complexities with assessment data, as various factors can influence both validity (accuracy and soundness) and reliability, as have been identified. Other issues can also impact the interpretation and the practical application of the assessment data in the choice of most appropriate model of care for an individual. The Hunter experience revealed several such factors at work in the Stage 1 redevelopment that involved difficulties in communication and poor collaboration, as well as fear of lack of medical and other resources to meet client needs and issues around staff training.

Communication: Lack of communication had been a significant barrier to the validity and reliability of the assessment process in the Hunter. There has been historical lack of information about who makes decisions and decision criteria. Participants expressed frustration over no feedback and feeling “kept in the dark as to what is happening”. This was compounded by a genuine lack of information available especially as 2018 looms.
Community Resources: Concern was expressed by members of the various focus groups and a number of interviewees over the adequacy of Hunter based community resources to cater for the complexity of health care, ageing and behaviour needs of the LRC client population that have yet to transition to the community. Future difficulties accessing GPs who do not have disability specific knowledge and medical specialists and allied health practitioners were raised repeatedly. Similarly, difficulties people with ID have when accessing local GPs in medical centres where consultation time is short were highlighted, as clients can experience heightened anxiety and communication difficulties. In contrast, the Director, Disability Hunter stated a network of GPs has been established that group home staff continue to use and extend, but there is a shortage of RNs. The need to educate medical practitioners was noted as important. Although not the focus of this report, the fear of lack of skilled personnel and access challenges were and may continue to be an additional factor contributing to the advocacy of clinical staff for use of the SSL model for a number of clients in preference to the DSW model.

The NSW Nurses and Midwives Association focus group raised the issue that during Stage 1, The Stockton Service Improvement Team created two positions for a one year project working with Hunter Primary Health that enabled two Clinical Care Coordinators (a nurse and a speech therapist) to research and link clients with GPs and Allied Health professionals in the community where they would live. Hunter Residences Group Homes received this service and a GP was identified before the project ceased, one week prior to last houses opening. The NSW Nurses and Midwives Association focus group stated they were keen to know results of the project which may or may not be an important initiative to replicate, but no feedback has been provided on the project’s success or whether a continuation of the project is required in the context of other initiatives with NSW Health and full implementation of the NDIS.

Staff Training: Hunter management stated that previous to 2017 there had been limited education or staff training provided to Stockton LRC staff regarding the changing scene in disability including deinstitutionalization, the advantages of community living and the DSW role. Not surprisingly, RUNMs and RNs from the LRC involved in the assessment process were therefore largely ignorant of the knowledge and skill level of DSWs, and of the details of the Framework for skilling the NSW disability workforce and the Health Procedures Register, which no doubt contributed to their concerns and advocacy for SSL services over the DSW model. This lack of knowledge and understanding negatively impacted the assessment process in that it limited collaboration and consultation.

Another critical area highlighted by RUNMs and nursing staff was the importance for people who have high and complex needs who are being allocated to a DSW model, that hands on training is received by the DSW with the specific client/s prior to the move to
ensure the specific medical, behavioural and/or ageing supports necessary are sufficiently provided during and beyond the transition. This should be recorded on the assessment spreadsheet.

5.11 Family Interviews

Seven family members from Stockton and surrounding areas were interviewed.

1. No one had specific information arising from the assessment tools.
2. The majority trusted the staff to do the assessments; there were several cases where staff had shared with them:
   - “Assessment issues like health, medication, epilepsy... discussion about these things on a yearly basis. X is happy that he is sent a summary of results, needs and requirements; ...comfortable with assessment .... Happy to put trust in those that send reports”.
3. All family members initially wanted RN staff 24/7 although there were some variations and changes over time:
   - “Definitely staffing; ... needs a registered nurse to do enemas and medication; overview feeding as choking can happen ...”
   - “...have not been told which staff will transfer into the group home; staff also waiting to hear; very necessary to have a male registered nurse as 24/7 care is needed otherwise X will end up in jail again; worried that staff of the present quality will not be available as their wages are higher than what is paid in NGO’s”.
   - One person had moved out to Waratah and family were satisfied with DSW staffing and access as it was different to have live-in staff in a home setting.
   - One family stated their loved one required an AIN or RN but suggested an RN could be shared between two houses.
4. All interviewees were frustrated that the redevelopment process had taken so long.

5.12 Conclusions based on consultation phase data

In review of current practice, despite application of the same assessment framework and assessment tools, there was a disparate experience between the Metro and Hunter regions. While there was general consensus that the assessment process was effectively applied at Metro Residences, this was not the case for Stage 1 Hunter Residences where validity and reliability issues were raised.
All participants in the consultation were able to articulate the steps in the transition process but were less able to articulate how the assessment of health, behaviour and ageing occurred and these issues indicate there is a need for written guidelines that specify the purpose of the assessment, clarify roles and responsibilities and clearly outline the steps involved in the assessment process required to determine the model of care. A flowchart could be helpful in this regard.

**Critical Components of the assessment process**

- A collaborative team approach is required, with clear roles and responsibilities clearly outlined for the various participants (CRO, RUNM, etc), and including who is responsible for clinical decision.

- Clear written guidelines are required for the assessment process and use of the Client Support Needs spread sheet. People involved need information written in plain English (for staff and families). Documents need to include instructions on what the spread sheet is – its purpose, and how to use it; and the steps to follow in the decision making especially when there are possibly contentious areas that require clinical judgment.

- Decision points should be clearly identified. These trigger meetings to discuss client/s but also require clear indication of what staff are being asked to sign off on. Previously in the case of Hunter, there was poor understanding of what a signature agreed to, especially if medical needs may have increased or decreased since the assessment information on file was recorded.

- The team needs to case conference outcomes (ranging from a client can be independent through to assessment needs advocacy, or specialist care).

- There can still be confusion regarding how to make fine line decisions using the assessment information summarized on the spread sheet, which only indicates if a condition is present or absent and does not indicate range and severity of a problem. For example, a client may have severe dysphagia, and a history of several bouts of related pneumonia, combined with regular vomiting. Cases such as this should trigger further clarification, and collaboration with nursing staff who draw on evidence based practice that uses both assessment data combined with clinical decision making to determine the level of support required – comprising the intrusiveness or intensity, frequency and sustainability of support required.

- The decision making process regarding the model of care needs to be continually open to revision, with information welcomed by all relevant parties. This requires communication and cooperation between all parties at every step of the process.

- There is need for a clear escalation path to be formalised so concerns if and when they occur can be addressed:
- Minutes of meetings are to be distributed and agreed to, with clear documentation if a person disagrees and why they disagree.
- A complaints mechanism is required including an open-door policy with information provided straight to the Director of the LRC.
- If unresolved at the previous level, the complaint should be passed on the Executive Director and Deputy Secretary.

### 5.13 Assessment process reviewed against good practice criteria

The literature identified a number of guiding principles and good practice criteria, and the assessment process was reviewed against these as follow:

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Evidence and Comments</th>
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<tbody>
<tr>
<td><strong>Person-centred</strong></td>
<td>Strong evidence in the transition process. Some evidence person centred tools also used in assessment process at Metro Residences</td>
</tr>
<tr>
<td><strong>The framework of human rights</strong></td>
<td>FACS ADHC Policies underpinned by human rights framework</td>
</tr>
<tr>
<td><strong>Focus on function &amp; Quality of life (QOL)</strong></td>
<td>Strong evidence Transition process focuses on assessing and improving function and quality of life. Some evidence assessments especially Behaviour Support consider QOL, and rationale for choice of DSW model to improve individual function and QOL wherever possible.</td>
</tr>
<tr>
<td><strong>Evidence based Practices:</strong></td>
<td>Some assessment tools less helpful – Recommend use of CHAP plus some additional information (listed section 6.2, p.39).</td>
</tr>
<tr>
<td>- The most reliable, valid tools assessment tools used</td>
<td>• Good evidence for specific management plans e.g. epilepsy, asthma</td>
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<tr>
<td>- Process and principles by which the tools are implemented</td>
<td>• Variations in how well documents were completed</td>
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<tr>
<td>- Education &amp; training of staff</td>
<td>• Staff need specific instructions and training in each tool</td>
</tr>
<tr>
<td><strong>Quality Health Assessment Tools:</strong></td>
<td>Variable – recommend use of CHAP</td>
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<tr>
<td>- New disease detection</td>
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<td>- Age and gender specific preventative screening</td>
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<tr>
<td>- Health promotion</td>
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<tr>
<td><strong>Phased Approach to Assessment</strong></td>
<td>Variable evidence Risk management plans list all risks and were not specific enough highlighting important individual risks.</td>
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<tr>
<td>- Risk assessment for behaviour that challenges</td>
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<tr>
<td>- Ageing risk assessment for frailty, falls and dementia</td>
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<tr>
<td><strong>Ongoing, Flexible Assessment Process</strong></td>
<td>Strong evidence was applied at Metro Residences</td>
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<tr>
<td><strong>Collaboration with Family and Service Providers</strong></td>
<td>Hunter weak - lacked collaborative process to facilitate this</td>
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<tr>
<td>Strong evidence in the Transition process</td>
<td>Families trusted staff to complete clinical assessments, some informed of results.</td>
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<tr>
<td>Service providers - evidence in Metro,</td>
<td>Poor engagement - Hunter Stage 1</td>
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<tr>
<td><strong>Explicit Organisational Procedures and Policies</strong></td>
<td>Require written guidelines for the assessment process to clarify these areas</td>
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<tr>
<td>- Organisational structure</td>
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<td>- Clear decision making frameworks</td>
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<td>- Transparent policies</td>
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<tr>
<td><strong>Promotion of Preventative Health</strong></td>
<td>Variable – recommend use of CHAP</td>
</tr>
<tr>
<td><strong>Behaviour that Challenges</strong></td>
<td>Evidence of PBS plans and Client Risk profiles comprehensive Metro</td>
</tr>
<tr>
<td></td>
<td>Evidence of PBS plan and risk profiles dated 2016 for two clients Hunter</td>
</tr>
<tr>
<td><strong>Disability and Ageing</strong></td>
<td>Evidence of some Health Care Plans and Risk Management Plans. Some plans missing.</td>
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6.0 KEY FINDINGS: ANALYSIS & EVALUATION OF TOOLS

This section addresses the key deliverable stated within the Specification:

- A review of the current process and tools / checklist used to assess the support needs of residents relocating from an LRC to a group home to ensure that they are fit for the purpose they have been used.

This appraisal was done by Dr. Seeta Durvasula, with the intention of reviewing the effectiveness of these tools for determining the level of medical support in the transition of people with disabilities (with focus on complex and high needs, aging, and behaviours of concern). The research team requested documentation of any guidelines or processes that had been followed in the initial assessment, for ongoing risk assessment, and in any subsequent evaluation of processes. However, throughout the research project it became clear the processes were varied. This is most tangible in regards to the individual cases provided for review. Therefore, in addition to the analysis of the tools, four client files from Metro and five from Hunter residences were included for analysis. The aim of this was two-fold; to determine:

- Whether the current tools and process adopted by ADHC adequately assess whether residents require immediate and constant nursing support as part of their supported accommodation.
- Whether the clinical procedures, guidelines and checklists as found within client files are relevant or sufficiently comprehensive in making these assessments.

Four tools were supplied with various documentation in order to represent current practice:

- Additional Health Care Needs Assessment tool;
- Audit of Health Status and Health Care Planning; and
- Framework for skilling the NSW Disability Workforce.
- Future Staff Levels Scoping tool / Excel spread sheet

Recommendations have been provided at the conclusion of the document, which reflect both the literature and this expert opinion.

6.1 PROVIDED TOOLS:

6.1.1 Additional Health Care Needs Assessment Tool

- Features of tool

- Used by RNs or CNEs, preferably those who know the client
- Used when client identified to have additional health care needs that can’t be met by current staff.
- Develops a profile of health care needs of resident, highlighting those that require nursing support – by using existing support plans and assessments
- Document is reviewed three monthly or if any changes to health needs or support plans by CNE
- Grid – states conditions (can add additional), type of treatment required for each, who is responsible for this (RN or specialist or DSW) and frequency of treatment, source of information (e.g. health care plan, CHAP, Behaviour support plan etc)
  - Who identifies clients with additional health needs who need this assessment?
  - Tool is reasonably comprehensive, as it allows for additional conditions and supports to be added as required.
  - Requires three monthly reviews or if condition changes – this is a good feature
  - It relies on reports by others, rather than direct assessments by RN or CNE, so assumes existing reports are comprehensive and accurate.
  - Should ideally include facility for RN/CNE to indicate need for additional information to fill any gaps.
  - Still not clear how the results of the grid translate to decisions about nursing support.
  - Note: “Gastrostomy” frequently misspelt as “Gastonomy”

### 6.1.2 Audit of Health Status & Health Care Planning in Supported Accommodation in “Metro Residences”

Although this is presented within the Specification as a tool, it is an audit of health status of people, and particular to Metro residences. The audit used three main measures to assess health status and support requirements. The measures used are listed below with comment:

- **Concord Health Status Category Scale** (Appendix 2, p.33)
  - Developed for the general population and validated with ID physicians, but not validated against outcomes
  - Used to determine complex planning needs
  - Easy to use, give a score, is short
  - Not all serious issues are included e.g. (this is not a full list)
    - Dysphagia with aspiration or risk of aspiration. Person may not have PEG in place, but has complex care needs - ensuring accurate texture modification of food and fluids; close supervision
at mealtimes; need to recognise early signs of aspiration pneumonia

- Chronic lung disease – need for regular nebulizer therapy, recognition of early signs of deterioration
- Dementia – increasing support needs
- Tracheostomy / colostomy

- Level of severity and criteria / definitions need to be included e.g.
  - “Active epilepsy” – what does this mean? 1 seizure in the last 12 months? 1 seizure a month? 1 seizure a week? Several seizures a day? The first two may not indicate seriousness, but the latter invariably do.

- The scale indicates that if more than 2 serious conditions, need RN care, but people with 1 unstable serious condition will also need RN care – e.g. unstable diabetes, frequent episodes of aspiration pneumonia, chronic renal failure requiring dialysis.

- Does not take into account changing needs via ageing or disease progression.

- Conclusion - not a useful tool for this population.

- **FIM** (Appendix 1, p. 32)
  - This is a tool used in the rehabilitation population to determine function and cognition, usually in those with acquired disability. The report states that users must be accredited in its use.
  - Advantages – validated tool, but not certain if it is validated in people with intellectual disability.
  - Items such as comprehension, problem solving, memory or cognition are likely to need specialised assessment in people with intellectual disability.
  - Conclusion – not recommended for use in people with intellectual disability, especially when there are multiple adaptive functioning and support needs assessment tools developed for people with intellectual disability – e.g. I-CAN

- **Need for RN in Health Care Planning** (p.10)
  - Using 4 prompts for each client, numerical values were assigned to indicate the level of need for an RN to be involved in special Health Planning
  - The criteria were:
    - Complex medications prescribed
- Complex procedures needed
- Staff members are not confident in their skills and would like more advice
- Staff have communication difficulties with health practitioners or families
  - Using these criteria, clients were assigned a number 1-4
    - 1 – Needs RN for care, liaison or planning daily or weekly
    - 2 – Key worker needs to involve RN in planning at least monthly
    - 3 – Key worker needs to involve RN in planning at least monthly
    - 4 – Key worker should not need to involve RN in health planning
  - While this appears to be a useful tool, there are no definitions of complex medications or complex care in the report. It is also not clear how the 4 criteria translated into a numerical values indicating level of need for RN involvement.
  - This tool does not seem to have been validated

### 6.1.3 Framework for Skilling NSW Disability Workforce (2010)

- Describes procedures to be followed to include a procedure in the Health Care Procedures Register and for training of DSW in performing the procedure.
- The Framework was endorsed by an external medico-legal process in its development. The requirements outlined in the Framework represent a reasonable approach. However, it is desirable to include how the DSW can get back up if there is a problem in doing the procedures.
- This is a 2010 document with a 2012 updated Health Care register, which will require review to add other procedures and or delete/ modify some that may be redundant because of technology improvements, changes in treatment practices etc.

### 6.1.4 Future Staffing Levels Scoping Tool/ Summary spreadsheet

- This is a table of individual client’s health conditions and determination of staffing needs for clients.
- The summary only records Yes or No for the items - No indication of severity of conditions (e.g. mental health – Y/N – this could be mild anxiety or poorly controlled schizophrenia).
6.2 RECOMMENDATIONS RE: TOOLS/DOCUMENTS

Despite the Specification listing the four tools, the main health assessment tool used within the Metro client files was the CHAP. Therefore, this tool was included for analysis. It is noted that the CHAP tool is not used in the LRCs but is used by Districts and NGOs.

6.2.1 The CHAP

- Staff need to be trained in completing their sections accurately and completely.
- Reasonable assessment for health, but needs some additional information/clarification. It is recommended that a Health Care Action Plan be included to add specificity to the physical activity.
- Version 2010 – need updated version (version 14 – 2014) or another tool.

Additional items for health assessment:

- physical activity levels – 2014 CHAP only asks does the person get enough exercise, but does not say how much is “enough” – staff need to use the more recently developed guidelines outlined in the Good to Great (2016) manuals and supporting material to ensure greater clarity in describing client physical activity diet – staff need to use information contained in the Good to Great: Nutrition and Swallowing Guidelines about the elements of a healthy diet
- changes in function/cognition
- sleep disturbance
- signs of sleep apnea
- falls

- All CHAP assessments need to include a physical activity plan that draws upon the National Physical Activity Guidelines, modified according to the impairment/functioning of the individual.
### 6.2.2 Health Care Action Plans (HCPs)

- HCP needs to be re-written to suit DSWs if clients are to go to DSW model group homes – i.e. in lay language, give clear instructions.
  - For example, definitions of epilepsy and osteoporosis in one plan are in medical language.
  - With regard to one client's asthma, the instructions are to review by MO "if needed"; monitor SaO2 levels "if unwell". These instructions are too vague with no criteria for "unwell" or "if needed"

- For specific actions, need to indicate who is responsible for these and review dates.

- HCPs need to include preventive health measures – e.g. physical activity, mammograms, bowel cancer screens. A comprehensive assessment tool such as the CHAP would identify these.

CDS has been advised by FACS that clear instruction in lay language are included in the Good to Great Chronic Disease Guidelines and Health Promotional Guidelines (2016). A procedure may be required to ensure regular updating and use most recent Guidelines occurs as a matter of practice.

### 6.2.3 Epilepsy Management Plans

- Need to be individualized.

- Advice when to call ambulance is generic and not individualised (e.g. includes diabetes, pregnancy, even if the person doesn't have these). This is not good practice, as in an emergency you need have relevant information immediately at hand. Also not person-centred.

- Emergency Protocol section - Emergency medication – says “see Medication chart”.
  - In an emergency, staff should only need to refer to one document, which lists emergency medications listed with doses and number of times to be given in the Epilepsy Management Plan, or attached to it.

- Refer to epilepsy Management Plan templates available from Epilepsy Society of Australia and others.

### 6.2.4 Asthma Management Plans

- Not all are well completed. In an asthma management plan, need to:
  - Describe what an asthma attack looks like in that particular person.
- Indicate any triggers for asthma in the individual.
- Outline what to do when well.
- Outline what to do when the person has a respiratory infection.
- Outline what to do in an asthma attack.
- Describe indications for prn medication.
- Indicate when to get medical help.

- As in Epilepsy Management Plans, would suggest having medications and their dosages listed in the actual Asthma Management Plan or attached to it, rather than saying to refer to medication charts.

### 6.3 GENERAL COMMENT ON DOCUMENTS

The multiplicity of documents is confusing and makes it less likely that all are filled in correctly, or read thoroughly. It was also noted in this review that some information is present in some documents, but missing in others. Suggest reviewing whether information can be consolidated into fewer documents.

Client Risk Management Plan in many instances lists multiple potential risks without highlighting specific important risks for that client. For example, in one client, the plan is 13 pages long and includes potential but unlikely risks such as sharps and flammables in a person who is in a wheelchair. Listing every potential risk means that important risks to life and safety are buried in this volume of material. For this person, the life threatening risks are with his malnutrition and aspiration and these are the ones that should be emphasised. All health conditions related to this person are listed, whether important or not. The management of these is better in the Health Care Plan.

CDS understands that concerns about confusing documentation are likely addressed by the proposed implementation of the Good to Great Framework within Hunter Residences.

### 6.4 CASE STUDIES - EVALUATIVE REPORT

A sample of client files were reviewed to determine the effectiveness and application of the assessment process and tools/checklist used to assess the support needs of residents relocating from an LRC for decision to recommend an SSL or DSW model.
Four client files were reviewed from Metro Residences in order to assess the tools used in practice, and assist in determining what was possible for nursing staff to determine via such evaluation. Details for the five case studies are located in Appendix 3.

Overall, it was clear that it was:

- Variable in how well documents were completed
- Staff need specific instructions and training in each tool
- There were some missing Health Action Plans from clients’ records

Five client files were reviewed from Hunter Residences in order to assess the tools used in practice, and assist in determining what was possible for nursing staff to determine via such evaluation. Details for the five case studies are located in Appendix 4.

All five clients had complex health care needs such as dysphagia with special feeding and hydration requirements, risk of choking, nutrition problems, severe reflux and other options to oral feeding not available. There were also aging needs. However, no one was assessed as having intrusive features requiring a medical model to support their needs, and all were assessed as capable of being managed under a DSW model.

Overall, as with the files supplied as current for the Metro residents:

- There was variability in how well documents were completed with various errors, omissions and incompleted sections, and some not signed off
- Staff need specific instructions and training in each tool including provision of dates and review dates on files
- Client Support Needs grid lacks definitions and criteria e.g. complex health conditions are not defined
- Review of data indicates at least two persons (Cases A and E) would not be suitable for a DSW staffed group home due to specific health conditions being unstable and/or risks identified indicating medical vulnerability.
7. REPORT RECOMMENDATIONS

The following recommendations are presented, derived from analysis of the current practice at both sites and considering good evidence based practices as identified in the literature.

**Rationale: The Need for Guidelines**

The need for guidelines is stated within the *Framework for Assessing Standards for Practice for registered nurses, enrolled nurses and midwives* (2015).

Complex health conditions are currently not defined. It is recommended that FACS develop criteria to define what a complex health condition is, taking into account not only the actual condition, but also its severity and interaction of multiple conditions in the one person. Another consideration is the interaction of multiple health needs of the residents within a group home. Here the threshold for defining complexity may be lower. So, while any individual's health conditions may not be complex, in the context of living with others who also have health risks, the complexity within the group home increases. This needs to be taken into account when determining staffing structure.

**Develop Written Guidelines for the Assessment Process**

There is an urgent need for written guidelines that specify the purpose of the assessment of complex health, behaviour and ageing needs and the use of the Client Support Needs spread sheet, as distinct from the transition Compatibility GRID. The guidelines should clarify roles and responsibilities of key stakeholders and clearly outline the steps involved in the assessment process required, and include use of the spread sheet to determine whether the SSL service or DSW model of care is most suitable. These should also include:

- Definitions for various terms such as complex health;
- Procedures for handling differences of opinion re interpretation of data;
- Procedures for updating data when health conditions and or behaviours change or there is a clear escalation path that may require a change in model;
- Criteria and procedures to facilitate clinical judgment for physical health, mental health, behaviour and ageing support needs, especially when the support needs are sufficient to present a risk to self and /or others. Criteria should address intrusiveness, frequency and continuity of support, and patterns of need for an individual and/or group of people that would affect sustainability under the DSW model;
- A flowchart outlining the steps could be helpful.
Staff Who Know the Person

There is a need to ensure that at minimum one staff member in the assessment process knows the person well and understands their unique communication as well as health care and/or behaviour and ageing support needs. Consultation with clinical staff and use of clinical data is also imperative when assessing complex health needs.

Develop and Apply a Decision Making Framework

A draft decision making framework is proposed for use in cases where clinical judgment is required or where conditions are complex and require further consideration to be able to make an informed decision regarding model of care.

- Criteria already being used in Metro and the Hunter District covering the factors of intrusiveness/intensity; frequency and sustainability of condition/s and patterns of change.
- Collaborative practice with all key players involved in open dialogue.
- Use an ongoing up to date assessment information that complies with the Good to Great Policy Framework.
- Assessment of level of risk based on likelihood of an incident occurring due to the condition/s and the severity of the consequences of an incident
- Accountability that identifies who was involved, the final decision, persons responsible and timelines etc.

A Draft form is provided in the Appendices for consideration. (The level of risk matrix is adapted from [www.safetyline.wa.gov.au/institute/level1/course6/lecture93/](http://www.safetyline.wa.gov.au/institute/level1/course6/lecture93/))

Consider Using Standard Validated Tool

The “Comprehensive Health Assessment Programme (CHAP)” is used within some ADHC client files, but not all. It is recommended that this tool in its most recent form be included in all assessments and used as the standard. This is not only one of the most comprehensive tools, but it also scientifically validated.

Under the Medicare Benefits Schedule (MBS) there are items for health assessments in people with intellectual disability (items 701, 703, 705 and 707). Items to be included in these comprehensive health assessments are listed on the Medicare website- [http://www9.health.gov.au/mbs/fullDisplay.cfm?type=Item&q=701#assocNotes](http://www9.health.gov.au/mbs/fullDisplay.cfm?type=Item&q=701#assocNotes). The CHAP encompasses these requirements and in addition provides a more detailed and structured assessment.

The CHAP is designed to encourage communication about health care needs between the person with ID, the care provider and their GP to facilitate the co-ordination of healthcare
which in turn supports a more effective assessment process. The support staff complete one part of CHAP and doctor completes the other. From this assessment process, a Health Care Plan can be developed.

**Ongoing Staff Training**

There is need for ongoing basic and advanced staff training for LRC staff regarding the use and recording of health care, behaviour and ageing information for specific assessment tools. A review of client files found some existing documents are inconsistently completed and it is recommended staff have training in this area. There is also need for staff training to work with particular clients who have high and complex needs at the critical time of transition to ensure support needs are correctly and competently met.

**Liaise with PHNs to Ensure Annual GP Health Check**

Ensure that regular health checks are being done before and after people are living in the community. This will be a key strategy – as previously this was not considered necessary by all. However, we know that by doing health checks on people with a disability, this increases the health ‘actions’ (Byrne et al, 2015). Studies cite evidence around doing an annual GP health check (Leibel et al., 2009, and Bowers et al., 2014). As already discussed, the CHAP is a tool that can be used for these annual health checks.

**Consider Implementing Risk Assessment for Behaviour**

As per the literature review, there should be risk assessments for behaviours that challenge. (See NICE Guideline recommendations; Bakker van-Gijsel et al 2017; Slowie, D., & Martin, G. (2014)). Consider adding a column to the Client Needs Profile to indicate specific and individual risks.

**Specialists Involved in Evaluation of Support Level**

It is highly recommended that FACS continues to negotiate with the Department of Health to establish regional specialised health services. While in principle people with disabilities should be able to access mainstream medical supports, for people with complex considerations related to health, aging and/or behaviour, specialist health services are often required - in particular, access to medical and allied health specialists who have experience with intellectual disability. These services support general practitioners in providing health care to this population. The Sydney region currently has some specialised health services for people with intellectual disabilities, including two operated by the Centre for Disability Studies. These services provide comprehensive physical and mental health assessments and recommendations to GPs, other health services, families and disability service providers to co-ordinate high quality care.
8. REFERENCES


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LRCSSL-SS Guidelines: Management of risks to safety, health and wellbeing in the transition of residents and staff from ADHC LRCs (Draft Version 5, 24.11.2014) (Currently under review).

Document includes Attachment 1: Potential risks identified in the transition of people from LRCs

Attachment 2: LRCSSL-SS Transition Gateway Certification

Attachment 4: Example Risk assessment (choking on food, pneumonia, bowel obstruction, Medication errors

Attachment 5: WHS risks that may need to be considered in establishment of new group home (from LRC redevelopment)

Transition Timeline HRCU-LRC-Resident (FACs NSW) – roadmap for transition 26 week period with CRO, LRC and NGO involvements
APPENDIX 1: LITERATURE REVIEW

This section addresses the key deliverables in the Specification as stated:

- A review of current literature and consultation with jurisdictions to identify any other issues that should be part of this consideration in NSW.

In addition it notes,

- A review of current literature and consultation with other jurisdictions will benchmark practice in NSW with other jurisdictions and identify potential improvements or processes that could be adopted in future assessments or in planning supports. There is however limited time available to introduce significant changes unless they are clinically necessary to ensure people’s safety in their new accommodation.

The research questions and keywords that formed the basis of the search strategy were:

**Q1:** What are the features of good nursing-based practice in supporting people with a disability living in community based accommodation?

**Q2:** What are potential models or frameworks that can be put in place to facilitate nursing-based good practice?

**Literature Review Framework and Approach**

The framework of realist review methodology (Saul et al. 2013; Pawson et al., 2002) was used for this literature review. Realist review is an established methodology that can be particularly useful to inform policy or practice within a short time frame. Realist reviews are practical and can include an approach where experts refine the questions and redirect the approach throughout the review. The key stages of a realist review (Pawson et al., 2002) are:

- identifying and developing the question(s)
- searching for suitable literature (studies, guidelines, evidence based summaries)
- appraising the quality of the literature
- extracting the data or information
- synthesising the information
- disseminating the findings

Alongside the realist review approach, a ‘top-down’ approach was used, as described by Straus & Haynes (2009), where more highly synthesised evidence-based resources were sought first. Figure 2 shows the possible levels of synthesis for evidence-based resources.
The reason this approach was used was (1) that initial literature search of databases for primary studies yielded no useful articles and (2) the nature of the information sought lent itself to seeking high quality guidelines and international examples of best practice, rather than primary studies.

Figure 2: Top Down Literature Approach

Search Strategy

A preliminary search of databases was performed, and resulting keywords were developed. The CDS team was then asked to provide feedback and add to the possible keywords. The main database searches were performed for 3 separate domains: behaviour, ageing and health. The reason for this is that preliminary database searching found that these keyword and MeSH terms were more likely to result in relevant records for this review. These domains were also highlighted as key areas in the tender document. Although separate searches, and keywords were performed, the results in Figure 1 display a combination total number from these searches.

The following databases were searched for English language records published between January 2007 and September 2017 (current).

- MEDLINE
- CINAHL (Cumulative Index to Nursing and Allied Health Literature).
- ProQuest Nursing and Allied Health
- ProQuest Health and Medical
Ø Cochrane Collaboration of Systematic Reviews
Ø TRIP database
Additional sources were separately searched using keyword combinations according to the 3 domains (behaviour, ageing, health).

Ø National Institute for Health and Care Excellence (NICE) guidelines
Ø Agency for Healthcare Research and Quality (AHRQ)
Ø Database of Abstracts and Reviews of Effects (DARE)
Ø Joanna Briggs Institute (JBI)
Ø Citation and related article searching on key articles using Google Scholar
Ø Grey literature searching

**Inclusion Criteria**

Records were included if they were:

1. Published between a certain period (2007-current)
2. Available in Full text
3. Answered or was highly relevant to, question 1 or 2 of review questions
4. High quality guideline or other synthesised evidence-based resource (according to the Straus & Haynes, 2009 pyramid of evidence-based resources)
5. Applicability to the Australian setting was favoured.

**Search Results**

There were 1205 records identified as potentially relevant and meeting the inclusion criteria during database searches, and 955 records identified through other sources. After exclusion by title for records meeting the inclusion criteria, 19 records remained and 4 of these were excluded after reading full text. There were 5 articles that were retained and considered key records, and a further 10 additional records that still met the inclusion criteria however were of lower importance due to not being directly relevant for this review. The results and flow chart is displayed below.

For this project, the search process used reference lists supplied to CDS by FACs/ADHC. Comprehensive citation searching (for more recent articles) and related articles was performed and the 2015 NICE Guideline (Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges) was found. As this guideline was extremely high quality, inclusion criteria were then altered for searches related to behaviour.
1. More recent articles than the NICE guideline or
2. Articles that were not included in the NICE guideline but met the previous inclusion criteria

Searching in the ageing and health domains proceeded according to the inclusion criteria and top down approach detailed above.

Figure 3 – Flowchart of searches and included key articles
Guiding Principles

There were a number of key principles that emerged from synthesising the literature. These elements were considered important as foundations to developing and maintaining a robust assessment and support framework.

- **Person-Centred Approach**

  A person-centred approach ensures that the PWD is involved and considered at every stage of an assessment or support. They are central, and their perceptions, feelings, age, social situation and values should be a priority. In this way, any assessment, support or system needs to balance consistency (such as use of formal tools and decision making frameworks) as well as enough flexibility to uphold the person-centred approach.

- **Human Rights**

  The framework of human rights (detailed in the introduction), with particular focus on the rights of people with disabilities outlined in the United Nations Convention on the Rights of Persons with Disabilities should underpin any system developed. The Australian government has committed to ensuring that people with a disability have access to the standard of health as the general population, without discrimination.

  Nursing assessments and supports should recognize the autonomy and right to decision-making. Support should be available to facilitate autonomy and decision-making.

- **Focus on Function and Quality Of Life**

  “Priority outcome measures...should focus on quality of life and the protection of human rights” (Banks & Bush, 2016). There is strong consensus in the peer-reviewed literature that any ‘intervention’, be it an assessment of nursing needs or support provided, should have the clear goal of improving the PWD’s quality of life (Bakker-van Gijsel et al., 2017; Troller, 2014; Banks & Bush, 2016; Bowers et al., 2014). This is in line with the approach of the National Disability Insurance Scheme legislation (NDIS Act, 2013) that revolves around social and economic participation. When designing and refining assessment tools, it is recommended that priority is given to domains that will most improve a person’s functioning and quality of life (Bakker-van Gijsel et al., 2017). This will vary between individuals, and assessments should reflect this.

- **Evidence Based**

  It is recommended that assessments and supports are based on the best available evidence (Nursing & Midwifery Board paper, Bakker-van Gijsel et al., 2017).

  In health care, evidence based practice (EBP) is defined as the integration of best research evidence with clinical expertise and patient values (Sackett, Strauss, Richardson, Rosenberg...
Similarly, evidence-based behavioural practice (EBBP) entails making decisions for service delivery or care by integrating best available research evidence with practitioner expertise and other resources and the choices and preferences of those affected. EBP relates to the various levels/parts of assessing a PWD for nursing care including:

- The assessment tool itself – ensuring that the most reliable, valid tools are used
- The process and principles by which the tools are implemented
- The education and training of staff involved
- The organisational processes developed to support PWD in community-based settings longer term.

**Features of Good Practice**

There are a range of health assessment tools that can form the basis of a reliable, rigorous nursing needs assessment. Health assessments lead to increased detection of unmet health needs for PWD (Robertson et al 2014, Robertson et al 2011).

Three elements of health assessment tools are:

1. New disease detection
2. Age and gender specific preventative screening
3. Health promotion

It is important that these three elements are reflected in any assessment tool. The literature recommends using a quality formal assessment tool or to use the formal tools as a basis to construct a fit-for-purpose health assessment instrument. A recent systematic review by Bakker van-Gijsel et al. (2017) examined 20 available health assessment tools for people with an intellectual disability. The following domains of health were covered to varying degrees in the 20 tools reviewed.

- Abuse and sexual health
- BMI
- Behavioural problems
- Choking
- Constipation
- Epilepsy
- Falls/accidents
- Feet problems
- Reflux
- Hearing
- Heart
- Lungs
- Mental illness
• Oral health
• Osteoporosis
• Sleep
• Thyroid disease
• Visual impairment

The assessment instruments were found to vary greatly in design, content, size, and scientific quality. Only three instruments evaluated met effectiveness criteria in a randomised controlled trial. These were the “CHAP”, “Ask health diary” and “the Scottish health check programme”. No instrument met all the important quality aspects although all instruments pay attention to (new) disease detection, in particular ID-related health problem. Based on the review and taking into account the domains covered, two particular instruments were selected as of the highest quality and potentially superior to the others when used to construct a health assessment for people with ID to meet scientific standards:

- “Stay well and healthy – Health risk appraisal (SWH-HRA)”

The “SWH-HRA” consists of more than 20 subscales and has good face validity, criterion validity, test–retest reliability, and internal consistency (Hahn & Aronow, 2011).

- “Comprehensive Health Assessment Programme (CHAP)”.

The “CHAP” covers the total package of prevention activities and a significant number of GPs agreed to use the “CHAP” (Lennox et al., 2006). Moreover, a cluster randomized control trial (RTC) found an increase in health promotion, prevention and new disease detection in the group using the “CHAP” compared to the control group (Lennox et al., 2007).

N.B. The FACS Health and Wellbeing Policy approved the use of the Australian Medicare Assessment Form but no references were found to this regarding quality or validation in the Literature search (Also see further comment p.62).

• Phased Approach to Assessment

A number of authors recommended a phased approach to assessment and identification of support needs (NICE, 2015; Leibel et al., 2009; Bakker-van Gijssel et al., 2017) with strong emphasis on early detection. This is particularly important when assessing the need for support related to behaviour that challenges or issues related to ageing. The NICE Guidelines suggest that a risk assessment for behaviour that challenges could form part of a generic health assessment tool. The domains for inclusion for risk assessment for behaviour that challenges are suicidal ideation, self-harm, self-injury, harm to others, self-neglect, breakdown of family or residential support, exploitation, abuse or neglect by others, rapid escalation of the behaviour that challenges. Similarly in the domain of ageing, it is consistently recommended that risk assessment for frailty, falls and dementia
are done regularly (Apóstolo et al. 2017, Leibel et al. 2009, NICE guidelines, 2015; Troller, 2014). The phased approach sits well with a structured decision making matrix that determines the need for constant support from a registered nurse, as well as the elements of screening for behaviours that challenge and ageing related factors, which should be incorporated.

- **Ongoing, Flexible Assessment Process**

It is recommended that assessment is a flexible, ongoing process (Bakker-van Gijssel et al., 2017; NICE guidelines, 2015; Robertson et al., 2014; Troller, 2014). Along with a flexible, ongoing approach it is highly recommended that regular health checks be conducted for PWD as there is strong evidence suggesting that health checks are effective at identifying health, behavioural and ageing related issues (Bowers, Webber & Bigby, 2014; Robertson, 2014). The available literature reports on annual health checks by general practitioners, and found these to be effective at early identification of health problems and these appear to result in actions such as diagnostic tests (Robertson et al., 2014; Bakker-van Gijssel et al., 2017).

In order for regular health checks and ongoing assessment to occur, strong organisational structures need to be in place (Bowers et al., 2014) and close liaison with other health and service providers need to be fostered (Leibel et al., 2009). There is scant literature however, around what organisational structures and policy frameworks may lead to better outcomes for PWD (Balough et al., 2016).

- **Collaboration with Family and Service Providers**

It is recommended that family/carers and key staff related to the PWD be involved at each stage of the assessment process. Evidence suggests attending health assessments improves the knowledge and health prevention behaviours of carers and family (Robertson et al., 2014). Working with the people who are close to the PWD is an important part of the person-centred approach. Ideally, involving significant others in the assessment and feedback process will result in increased autonomy, decision-making opportunities and ultimately improved quality of life for the PWD.

It is recommended that strong links be established with other local health and service providers, and that these links are formalised in some way (Balough et al., 2016). This is particularly important when designing a new system that is unlikely to have enough funding on its own to deliver high quality, long term care. The authors of this report recommend embedding requirements in policy for local information about available service and health providers are collated, to ensure that clear and comprehensive health, nursing, and other supports are easily accessible for every PWD.
• Explicit Organisational Procedures and Policies

Organisational structure, clear decision making frameworks and transparent policies were found to directly impact on the way staff responded to screening, prevention and follow up diagnostic work (Bowers et al., 2014). Leibel et al. (2009) found that a lack of process evaluation measures, collaboration, documentation and training resulted in ineffective nurse assessments and interventions. Banks & Bush (2016) suggest that “interventions delivered as a part of care and treatment plans must be based on a clear, comprehensive and agreed formulation and diagnosis.”

The Australian Nursing and Midwifery Council have created a Framework for the Development of Decision-making Tools for Nursing and Midwifery Practice (2007) and recommend that clear guidelines underpin decision-making. In addition to ensuring that an assessment tool is reliable and comprehensive, the literature also suggests that policies and decision-making processes are explicit and embedded into policy.

• Promotion of Preventative Health

People with disabilities experience a number of risk factors for poorer health including obesity, Type 2 Diabetes, and high blood pressure (Balough et al., 2016; Robertson et al., 2014). Preventative health measures such as a healthy diet, physical exercise where possible and cognitive/mental exercise are as important for PWD as the general population (Troller, 2014). One of the key ways to promote preventative health is to involve the PWD along with their family/carers and key staff in the assessment and support process. There is consensus in the literature that any health assessment or support for PWD should have a large component of preventative health measures (Bakker van-Gijssel; Banks & Bush, 2016; Lloyd & Kennedy, 2014).

Specific Assessment Areas – Behaviour And Ageing

There was literature that related to the specific areas of behaviour and ageing amongst PWD. The good practice features above are all relevant to these areas. The information below expands these features, as related to the two specific domains.

Behaviour that Challenges

The high quality UK-based guideline (NICE guideline, 2015) includes practical and comprehensive recommendations for practice relating to people with a disability who have behaviour that challenges. This guideline is freely available online with both abbreviated and full versions. Specific factors to include in an initial assessment of behaviour that challenges is found in NICE 8.5.2 & 8.5.5 (pg 168 of full guideline). Selected key
recommendations relevant to this literature review are included below. However, the aim of any assessment of support should be to work out why the behaviour is occurring rather than simply identifying and intervening:

- Development of a behaviour support plan should occur as quickly as possible
- The PWD should be supported throughout the assessment process and person and family are fully involved in the process
- Everyone involved in conducting assessments at each stage should be skilled at knowing criteria for phases of assessment, and decision making points
- Initial assessment of behaviour that challenges should take into account a number of factors including the person's abilities and needs (in particular, expressive and receptive communication; any physical or mental health problems; and the effect of medications, including side effects; developmental history, including neurodevelopmental problems and behavioural phenotypes; sensory profile; response to any previous interventions for behaviour that challenges; environmental context etc.
- Carry out a functional assessment of behaviour (including clear description of behaviour; identifying the events, times and situations that predict when the behaviour will and will not occur; consequences or reinforcers that maintain the behaviour; hypotheses that describe the relationships between personal and environmental triggers, the behaviour and its reinforcers; and direct observational data to inform the hypotheses; baseline assessment data; reactive strategies etc etc.)
- There should be personalised feedback to PWD and their family/carers/advocate and the PWD should be supported to understand the feedback
- Recommendation to use a formal rating scale – e.g. Aberrant Behaviour Checklist or Adaptive Behaviour Scale
- A phased approach is recommended. After each phase develop a written statement – and if behavioural intervention, then develop a behaviour support plan (rec 33)
- Where behaviour of concern is severe or complex, assessment should be multidisciplinary and draws on skills from specialist services
- Regular assessment of risks for behaviour that challenges is recommended.

Disability and Ageing

There is evidence to suggest that health problems and disability specific problems are often dismissed by staff and family as ‘just getting older’ (Bowers et al., 2014; Troller,
These features may include physical decline such as worsening mobility or toileting and also changes in cognitive functioning. Dementia amongst PWD is thought to be under-diagnosed (Bowers et al., 2014; Troller, 2014). Moreover, people with Down syndrome are at increased risk of developing Alzheimer’s disease at a younger age than others in the population. Indeed, having Down’s syndrome is a significant risk factor for early-onset dementia. Adults with other ID may have specific needs for dementia-related care that, if unmet, can lead to diminished quality of old age. Baseline assessments and screening for dementia is therefore important, and specific tools suitable to people with intellectual disability include The Adaptive Behaviour Dementia Questionnaire (ABDQ), (Prasher, ASIM & Holder, 2004).

Health assessments that are specifically geared towards risk assessment for older people should be considered in conjunction with existing broad assessment tools (Leibel et al., 2009). This fits in with the phased assessment approach mentioned above, with risk assessments customised for individuals. Troller (2014) recommends the following for good practice:

- Preventative health
- Mitigating the effect of age on exacerbation of long term physical disability
- Addressing the risk factors for cognitive dysfunction
- Screening for cognitive decline
- Access to skilled assessment and management in situation where cognition declines
- Access to skilled assessment and management in situation where cognition declines
- Cohesive array of supports
APPENDIX 2: STAFF/FOCUS GROUP QUESTIONS

Staff Focus Group Questions:

- What do you consider “good practice” in assessing and interpreting the initial assessment tools to identify the level of nursing supports for health care?
  - Does initial assessment take into account support for general health needs? In what ways?
  - Does initial assessment take into account support for behaviours that challenge? In what ways?
  - Does initial assessment take into account support for aging? If so, how?
- Is there any system to ensure residents have a health check-up or GP visit? How regularly does this occur?
- What, if any, existing links are there with primary health networks?
- What is the process by which residents access their GP (how is a visit actioned)?
- Are there any ongoing risk assessments? How regularly do this occur? Does anything change as a resident ages?
- Are there any systems in place for communication between the various teams in relation to health support needs? Behaviours that challenge? Aging?
- Does the organisation offer any training in person-centredness?
- In your opinion, how is person-centredness practiced within the existing nursing support?
- Is there anything else you think we should know about the processes for determining the level of nursing support given to residents?

Additional Management Questions:

- Are there any organisational guidelines or policies around interpreting the findings of the existing assessment tools? If no, then how are the levels of nursing support determined?

Family Focus Group Questions:

- How often do you see your family member?
- What do you think their quality of life now that they are in the community?
- What do you think about their state of health after transition into the community? Why?
- What was the assessment process to determine the needs for your family member with a disability?
- Do you feel that it was accurate?
- How do you think the NDIS has impacted upon the process?
- Are you satisfied with your family member’s level of staffing; receiving the correct level of care? If not, what level of support do you think your family member should be receiving?
- Are there any services do you feel they are lacking?
- Do you feel their lifestyles are more person-centred?

For those who have not yet been moved into the community:
• What are your concerns with the assessment process?
• Do you know what kinds of assessments are being done to determine the type of accommodation to which they will be moving to?
• Have you been consulted during this process?
• What are your goals for your family member moving into the community? What are you looking forward to?

**Family Interviews**

Seven family members from Stockton and surrounding areas were interviewed

1. No one had specific information arising from the assessment tools
2. Majority trusted the staff to do the assessments; several cases of where staff had shared that with them
3. Assessment issues like health, medication, epilepsy... discussion about these things on a yearly basis. X is happy that he is sent a summary of results, needs and requirements; ...comfortable with assessment .... happy to put trust in those that send reports
4. All wanted RN staff 24/7 although there were some variations:
   a. Definitely staffing; ... needs a registered nurse to do enemas and medication; overview feeding as choking can happen ...
   b. “... have not been told which staff will transfer into the group home; staff also waiting to hear; very necessary to have a male registered nurse as 24/7 care is needed otherwise X will end up in jail again; worried that staff of the present quality will not be available as their wages are higher than what is paid in NGO’s.”
   c. One person had moved out to Waratah and family were satisfied with DSW staffing and access as it was different to have live-in staff in a home setting
   d. One family stated their loved one required an AIN or RN but suggested an RN could be shared between two houses.
5. All interviewees were frustrated that the process had taken so long.
APPENDIX 3: METRO CASE STUDY EVALUATIVE REPORT

A sample of client files were reviewed to determine the effectiveness and application of the assessment process and tools/checklist used to assess the support needs of residents relocating from an LRC to either an SSL or DSW model.

Within the interviews and focus groups, there seemed to be great disparity on which tools were used, and why they were used. Dr. Durvasula reviewed four client files from Metro Residences in order to assess these tools used in practice, and assist in determining what was possible for nursing staff to determine via such evaluation. We were advised that the original plans were all complete, and the plans sent for review are the most recent plans completed in conjunction with the providers. It is important to note that the tools listed within the Specification were not the only documents found within the files, and in these cases various issues emerged. Some may have implications in determining the level (or model) of support required within group homes.

Overall, it was clear that it was:

- Variable in how well documents were completed
- Staff need specific instructions and training in each tool
- There were some missing Health Action Plans from clients’ records

Metro Person A

This client was transitioned into a complex behaviour unit.

- Behaviour Support Plan is comprehensive – indicates specific risks and provides specific strategies; makes recommendations for new accommodation setting with respect to environment and supports required; Restrictive practices
- CHAP – completed fully
- Safety Plan - comprehensive
- Health Care Plan – see also below for general comments.
  - Contradictory advice - for suntanned skin (encourage to remain in shady areas when outdoors) and osteopenia (encourage daily un exposure for at least 20 minutes before 10 am or 2pm) – Please see recommendations for safe sun exposure:
  - Allergies – Staff to be aware of allergy and symptoms of anaphylaxis – but also should know what to do in case of anaphylaxis this is presumably in the relevant plan
  - Review dates for HCP not indicated

Metro Person B
The family members of this client were unable to be contacted due to a death in the family.

- CHAP – not completed fully by DSW – several sections left blank; not even ticked
  - Allergies - “unknown” – it’s either Yes (indicate allergy) or No
  - Date of last review of epilepsy?
  - Type of seizure – inaccurately completed
  - Women’s health – several sections left blank
  - Result of last vision test – left blank
  - Hearing test – left blank
  - Health Promotion and screening – blank sections
  - Immunisations – all left blank
  - Medical History, Family History, Health concerns – all left blank
  - Medical part completed well
- BSP and Client Risk Profile - by private providers – comprehensive
- No Health Care Plan seen

**Metro Person C**

The family member of this client was available for an interview. He was assessed as requiring a Disability Support Worker (DSW). After two years in the community, family were overall incredibly happy with the model of care, and the level of support provided within this model. In particular they believed the client had better eye and dental care than previously.

The family member spoken to remembered very little of the method of assessment. He did remember a questionnaire that allowed him to select the preferred location of the house. This was the only known consideration that the family were consulted on, however he recognized that other family members may have been involved in health concerns. He described the family as involved in the transition as they drove him to the location at various times, and talked about the move in positive terms.

In relation to the documentation that was provided:
- Part A CHAP well completed by staff
- Part B of CHAP completed by doctor
- My Safety Checklist / My safety management plan completed
- BSP completed
- Health Action Plan not completed
- Information about me - My History, Health Promotion Register completed

**Metro Person D**
No detail was supplied in interview about this client's assessment.

- CHAP completed
- Health action completed with review dates and who is responsible – detailed actions stated
- Information about me – Communication, Supports, Immunisations, Decision making, Health Promotion register etc. completed
- Safety Management Plan – comprehensively completed
APPENDIX 4: HUNTER CASE STUDY

Five client files were reviewed from Hunter Residences in order to assess the tools used in practice, and assist in determining what was possible for nursing staff to determine via such evaluation.

There has been significant contention over whether Group Homes should have been an SSL model rather than a DSW model because of the complexity of support needs of individuals involved. All five clients reviewed had complex health care needs such as dysphagia with special feeding and hydration requirements, risk of choking, nutrition problems, severe reflux and other options to oral feeding not available. There were also aging needs. However, no-one was assessed as having intrusive features requiring a medical model to support their needs, and all were assessed as capable of being managed under a DSW model.

Hunter Person A

  Physical Support Plan – Generally fine.
- **Cumulative medical history** – 1997 – 2013 – needs to be updated
  o Refers to hospitalisations but provides inadequate details as to their cause, treatments administered, follow up requirements or preventative strategies
  o Frequent mentions to injuries caused by falls without any reference to regular reviews and appropriate preventative strategies
  o Treatment for skin conditions and breathing conditions are listed under Falls/Accidents
  o Mentions fractures with no details about their cause
- **Recreational Activity preferences** – Under resources required for activities it does not specify level of staff support or supervision.
- **Client Manual Handling Plan** (Mobility Management Plan) 16.2.17 – Reasonable, but need to know that it is implemented and all staff follow the plan. From details provided about incidents, concerns arise that the person needs more support for mobility than is documented in their plan
  This particular plan has not been signed off by staff – see p.4
- **Client Annual Health Review 2015-16** – sections are either incomplete or in error
  o The medication regime suggests that the person has conditions that have not been listed, conditions are mentioned but not mentioned in other relevant documentation or support plans
  o Allied health reviews – not completed for S/T, Dietician, and Dental etc.
  Ticked neither yes or no
○ Risk factors for falls not completed – left blank. But other documentation records that the person has frequent falls.

- **Client Risk Management Plan 17.2.2017**
  ○ refers to risks that are not addressed in other relevant support plans

- **Health Care Plan – 20.3.2017**
  ○ Contains technical detail that is unlikely to be understood by people like DSWs without specific clinical training
  ○ medication relevant to behaviour support mentioned but there is not mention of relevant strategies to respond to the person’s needs
  ○ Asthma – terms used to describe the person’s support needs are vague and inadequate detail about actions required in response specific guidelines should be in the Asthma Management Plan, but are not.
  ○ Allergy – medications mentioned are not referred to in other relevant health care plans.
  ○ Nutrition and Swallowing Risk Checklist – 17.2.17 – completed thoroughly with appropriate actions

Other files sighted

- Placement history
- CT Progress notes
- Oral health Assessment 14.9.2016 (File is called “Transition assessment”)
- Physical Examination – 1/2/17
- Psychiatry report – file called “Axis 1” – 2014
- BS Summary (Behaviour support review summary) – 11.2.2016
- Communication profile - 21.2.17
- Client Risk Profile – 17.2.2017
- ID Page – 21.2.2017
- Lifestyle and Environment Plan 17.2.2107
- Medical records – 2014-17 (list of bloods, doctor visits)
- Health Summary Form – 28.3.2017
- Pain Assessment Nursing Tool (PANT) – 29.11.2016

(Client support needs grid) says “no complex health conditions” but these are not defined. Details in medical history and relevant Health Care Plans would suggest that the person has complex needs that may not be met in a DSW group home model.

**Hunter Person B**

- **Annual Health Review – 3.4.15 – 21.7.16**
  ○ reasonably comprehensive. The person’s medication regime would suggest that they have at least one other chronic condition that is not listed

- **Asthma Management Plan 10.1.17**
  ○ Reasonable description of asthma attack
  ○ Contains technical medical language and detail that is unlikely to be understood by people like DSWs without specific clinical training
  ○ Dosages of medications - says see Medication chart. Preferable to have these listed in the actual plan
As mentioned in other case file reviews – would suggest using Asthma Management Plan templates from Asthma Foundation

- **Annual Health Care Plan (HCP) - March 2017**
  - Can DSWs do some of these tasks if client is going to DSW model group home? e.g. checking oxygen saturation during asthma attack. HCP needs to be re-written to suit DSWs.
  - For specific actions, no mention of who is to do these; no review dates
  - General comments about HCPs – no mention of preventive health measures – e.g. physical activity, mammograms, bowel cancer screens - would suggest using CHAP – more comprehensive

**Other files sighted**

- Lifestyle Plan – 16.3.17
- Hospital support Plan
- Physical support plan – July-August 2016
- Safety Plan
- Client Manual Handling Procedure
- Psychology Transition Summary
- Behaviour Support Plan

**Client Support Needs Grid**

- Says no complex health conditions but complex health conditions are not defined

**Hunter Person C**

- **Epilepsy Management Plan / Seizure Chart – 19.10 2016**
  - Reasonably well completed.
  - Note – includes generic instructions including pregnancy, diabetes, even if it does not apply to this particular person.
  - Not signed off by DSWs or person responsible

- **Nutrition and Swallowing Risk Checklist – 22.7.2016**
  - Says client is not underweight – is underweight according to chart

- **Health Care Plan – 9.3.17**
  - Same mistake as another HCP, mentions medications administered for conditions that are not clinically appropriate, either the condition or the medication referred to is incorrect

- **Weight chart for 2017** – only 2 months completed

**Other files sighted**

- Client Manual Handling Plan (Mobility Management Plan) 7.3.2017
- Communication profile 9.3.17
- Continence Assessment – 10.2.15
- Client Risk Management Plan 9.10.16
- Client Risk Profile – 9.10.2016
- Cumulative medical history – 1995 to 2009
- MO Health Summary – 24.3.17
- Pain Assessment Nursing Tool – 2012
- Pre Lifestyle Plan review – 2016
- Physical examination – several years; brief
- Physical Support Plan – 9.10.16
- Preferred activities x 2 - 2017
- Transportation checklist - 2017
- Triple C Communication assessment – 2015
- Client Medical Notes
- Lifestyle and Environment Plan
- Lifestyle Plan x 2

Client Support Needs Grid

- Says no complex health conditions but complex health conditions are not defined

Hunter Person D

- Epilepsy Management Plan / Seizure Chart
  - Reasonably well completed.
  - Note – generic instructions including pregnancy, diabetes, even if it does not apply to this particular person.
  - Not signed off by DSWs
  - Has been “cut and pasted” from the file belonging to another person, and includes the other person’s name

- Cumulative medical history – 2005 - 2006 - Reasonably well completed

- Client Manual Handling Plan (Mobility Management Plan) 25.8.16 – Reasonably well completed

  - Reasonably good description of what asthma attack looks like for this person;
  - Contains technical medical language such as cyanosis that is unlikely to be understood by people like DSWs without specific clinical training
  - DSWs would need to be trained to administer oxygen by face mask.
  - This particular plan has not been signed off by staff

- Client Annual Health Review 17.11.2016 – reasonably well completed

  - Epilepsy - Response is stated as “administer psychotropic medications as prescribed” (mistake is in both HCPs)
  - Asthma management – clearly stated

Other files sighted

- Book About Me
- Continence Assessment
Client Risk Profile – 2016


Medical review – 1992 – Dr Helen Beange

MO Health Summary – 24.3.17 (spastic quadriparesis, asthma, epilepsy, kyphoscoliosis, dysphagia)


Pain Assessment Nursing Tool – 9.3.17

Physical Support Plan – 9.12.16

Activity preferences – 9.3.17

Seizure chart - 2016

Triple C Communication assessment – 2005

Contents page – green folder

Health Issues and Outcomes – 2009-2010

Client Medical Notes – 19997; 2000


Psychology Pre NDIA Assessment – 9.9.16

Lifestyle and Environment Plan

Lifestyle Plan x 2

**Client Support Needs Grid**

- Says she does not have complex health conditions but complex health conditions are not defined
- Under Staff Training Required - need to add training to administer oxygen in case of severe asthma attack – this is in the Asthma Management Plan

**Hunter Person E**

- Health conditions – lists a significant number of fairly complex health conditions
- **Annual Health Care Plan - May 2017**
  - also contains reference to another fairly complex health condition that required medical intervention
- **Health Summary Form** – completed March 2017. Health Summary Form template is very brief. Unsure about its purpose.
- **Subjective global assessment** (dietitian) – lists a condition that may have required significant medical intervention
- **Speech pathology report** – 8.8.2016 – lists a condition that may have required significant medical intervention
- **Mealtime Management Plan** – 17.2.17 – not signed off by DSWs

**Client Support Needs Grid**

- Says no complex health conditions, but complex health conditions are not defined.
• By all reports (see next point), client has several complex health conditions and could be medically vulnerable
• Details in medical history and relevant Health Care Plans would suggest that the person has complex needs that may not be met in a DSW group home model.
APPENDIX 5: DRAFT DECISION MAKING FRAMEWORK

MODEL OF CARE: DECISION MAKING FRAMEWORK

What is the issue of concern: Health Care – behaviour – ageing – combination:

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CRITERIA

Check against the following criteria:

☐ Is support required intensive or intrusive?

☐ Is the frequency of support two (2) or more times daily?

☐ Is support required sustainable in the longer term in DSW model?

☐ Is there any pattern of change (increased incidents, risks…)?

☐ Is there sufficient assessment data for decision making?

☐ Compliant with Good to Great Policy Framework

☐ Plan Documents are dated and not older than six months (Please list documents for this decision/or complete *2Document Handover Checklist attached)

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☐ Has a risk assessment grid been completed for issue of concern?

☐ Is there agreement between all key players on support level required and level of risk determined?

☐ Other considerations?

Other comments ---------------------------------------------------------------

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*See Metro Residences Documents/Reports Handover Checklist attached
Level of Risk

Determine the level of risk for the condition according to the likelihood of an incident occurring and the consequence of the incident if it occurs.

<table>
<thead>
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<th>CONSEQUENCE</th>
<th>VERY LIKELY</th>
<th>LIKELY</th>
<th>UNLIKELY</th>
<th>HIGHLY UNLIKELY</th>
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<td>LOW</td>
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</tr>
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</table>

Figure 4: Level of Risk Matrix
(This is adapted from www.safetyline.wa.gov.au/institute/level1/course6/lecture93/)

FINAL DECISION
Who is involved in the decision?
----------------------------------------------------------------------------------------------------------------------
What form will it take?
----------------------------------------------------------------------------------------------------------------------
Why?
----------------------------------------------------------------------------------------------------------------------
Who will be responsible and what timelines are realistic?
----------------------------------------------------------------------------------------------------------------------
How will the result be communicated?
----------------------------------------------------------------------------------------------------------------------

OUTCOMES
What outcomes/benefit has the decision had?
----------------------------------------------------------------------------------------------------------------------
What modifications are required, if any?
----------------------------------------------------------------------------------------------------------------------