Clinical Review Final Report. Prepared for Achieve Australia

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Achieve Australia (Achieve) engaged the Centre for Disability Studies (CDS) in 2018 to undertake a clinical review to understand, and appraise how the health status and care, daily living and well-being needs of residents within houses transferred from ADHC to Achieve are being met in line with best practice.

A mix of approaches were used for the clinical review including:

- A literature review and application to form best practice benchmarks for accommodation services
- An individualised health profile for each resident transferring to Achieve
- An assessment of the support in situ
- A report on resident and family perceptions of the support arrangements
- A report including recommendations for improving the support delivered to the new residents.

The quality of the literature was not adequate for setting “gold standard care” but was suitable to provide evidence-based “practice recommendations” applicable to Achieve covering the areas of assessment and planning, group homes culture, staffing and environment, health factors and behaviours that challenge.

Best practice is underpinned by commitment to the socio-ecological approach to disability, human rights, self-determination, person centredness and person centred practice and Quality of Life (QoL) for every individual. Various features of good quality group homes were also identified and summarised, including practices such as Active Support, positive behavior support (PBS) and a risk enablement culture, practice leadership and attention to staffing characteristics and ratios as well as the physical environment.

Assessment and planning generally and in the areas of health and behavior and ageing should be phased, ongoing and flexible, enable supported decision making and collaboration between family members and the service provider, and focus on quality of life. Four additional principles specific to health assessment were identified: use of quality health assessment tools; a flexible approach relating to health; having explicit organisational procedures and policies that correlate with local health provider systems; and the promotion of preventative health.

Individualised Health Profiles (IHP) were to be developed for 128 individuals with intellectual disability who transferred from ADHC services to Achieve, but consents were received for a total of 41 participants (representing 32% of the total cohort). Documents reviewed were developed at the point of transition and currency of documents in the houses requires clarification, as the overall demographic summary of those with completed files was compiled with the intention this can be used in future planning. The distribution of participants' ages was approximately normal with a mean age of 54.2 years. There were proportionally many more males than females in the sample. The average number of chronic health conditions in the cohort is 4.2, while almost the entire cohort would be defined as having polypharmacy; which is here defined as being prescribed four or more daily medications. A large proportion of the cohort have a long history of challenging behaviours, as evidenced by the number of behaviour support plans and types of behaviours. In total, only two participants (5%) had no reported behaviours of concern. Taking into consideration the health and behavioural assessment information gathered, it is estimated that most of this cohort have extensive support needs (63.4%), followed by moderate (24.4%) and then pervasive (12.2%) support needs.

Overall, data indicate an ageing cohort for whom health support needs will increase significantly with specialised nursing staff required. Future staff training needs will involve supporting an ageing cohort, providing dementia-specific supports, end of life care, and having policies and procedures around the storage and administration of S8 drugs for pain relief etc.

Support in situ was determined across nine houses through staff interviews with managers and direct support professionals as well as observations during planned house "walk throughs". Overall, the quality of life now being experienced by the participants in the sample was found to vary across houses, with some individuals enjoying a richer and more varied lifestyle since moving to their new homes while others are more isolated and/or experiencing high levels of behavior of concern. Numerous positives were identified as well as various challenges related to current and future staffing and the impact of casual staff, ongoing professional development needs, client compatibility and policies and procedures for the ongoing management of complex health, behaviour and ageing and communication across the organisation.

Resident perceptions of support arrangements were canvassed using Photovoice while and family perceptions of clinical support were gathered through Town Hall meetings and interviews.

Residents perception of their lives following the transition were ascertained using 137 photos that were intentionally selected by residents and staff for analysis, resulting in five theme that emphasised positives and negatives across: involvement in household activities; external activities; participation in everyday routines; communication and relationships; and high and complex health issues.

Families reported that many parents and even siblings are ageing and/or had other immediate concerns, making involvement for many difficult. Key themes that did emerge, however, highlighted the perception that staff are critical to facilitating overall quality of life either positively or negatively, and there was recognition that staff attitudes, practices and training could all affect overall well-being and impact on health and behaviour. Good communication systems between management, houses and families are also viewed as critical.

The research identified numerous strengths evident in current practice in health care and management, and in the support for residents who are also ageing and/or have behaviours of concern. Strengths are based on a highly skilled and dedicated workforce providing excellent support. The risk is this highly skilled and dedicated workforce may be lost to Achieve and to these clients with complex health and behavioural support needs.

The following recommendations are made to further improve service delivery and provide ongoing support to individuals who have complex care needs:

1. Staffing Recommendations

1.1. Adequate staffing levels and highly skilled staff are needed to provide the level of health care and quality of life for the residents, many of whom have complex health and disability conditions. Staffing should be consistent and not heavily reliant on casuals who may have little knowledge of the clients.

1.2. Staff training and continuing professional development (CPD) are essential to ensure quality health care and Achieve should fund these. It should not be up staff to fund all CPD themselves and take leave for it. For nurses especially, evidence of CPD at a certain level is necessary for maintaining their registration. Staff engaged in behaviour support will also require ongoing training and supervision to ensure knowledge and skills meet newly set capability benchmarks under the NDIS.

1.3. Staff training address supported decision making, person centred planning and active support, with on-the-job mentoring /supervision provided to ensure implementation.

1.4. Staff training address future training needs supporting an ageing cohort, such as dementia-specific supports and around end of life care, including policies and procedures around the storage and administration of S8 drugs for pain relief.

1.5. Establish a culture of trust between management and staff with regular communication. Currently, staff feel they are not listened to, and staff should feel able to provide honest opinions and feedback without fear of retribution.

1.6. Staff who have transitioned from ADHC should be regularly kept informed by management about their future beyond the two-year period – will their ADHC entitlements be honoured, will there be maintenance of current positions at the current professional levels?

1.7. Good and regular communication by Achieve management with families and individuals with intellectual disability is also essential.

1.8. Achieve management should ensure that adequate resources / equipment be provided and maintained for the houses.

1.9. As specialised nursing staff will be vital for the current and future support needs of the cohort explore ways to embed this funded support into NDIS plans.

2. Practice Recommendations – Health, Ageing and Behaviour

2.1. A clear set of evidence-based health and behaviour policies and procedures need to be developed or adapted and communicated to all staff.

2.2. A clear and documented process be established for regular monitoring of health, QOL, satisfaction (staff and clients) outcomes, with modification of policies as indicated. (For more detail on QOL see Section 8.15, p. 79-81)

2.3. Regular assessments be conducted in the areas of frailty, ageing, falls, dementia and mental wellbeing – using structured assessment tools. (For more detail see Section 4.10, p. 55-57)

2.4. Achieve use evidence-based health assessment tools (e.g. CHAP) and ensure each client has an annual health assessment.

2.5. Each client should also have a health care plan developed in consultation between a nurse specialist, the GP, and with input from the client and family. This should be done at least annually but may need to be modified more frequently if required. The health care plans need to have specific actions with time frames and the person responsible for implementing the actions. Each client should have a key staff member who is responsible for overseeing the implementation and monitoring the health care plan.

2.6. Each client needs to have an annual Nutrition and Swallowing Risk Checklist completed (this was ADHC policy). There should be guidance for staff on what to do if any concerns are raised in the checklist.

2.7. Preventive health measures, including regular screening (e.g. mammography, Pap tests, bowel cancer screening), updating immunisations, ensuring healthy eating and regular physical activity should be put in place, in consultation with GPs.

2.8. Medication management policy is vital, and all staff should have training in safe medication administration.

2.9. Ensure all residents have regular medication reviews by their general practitioner. A medication review by the pharmacist can also be arranged by the GP.

2.10. Conduct a clinical review of polypharmacy, where appropriate, as clients support needs change over time.

2.11. Achieve develop a palliative care policy which takes account of the future training needs for staff in addition to procedures for developing a palliative care plan where appropriate.

2.12. Ensure good documentation of health, behaviour and support needs, with actions, timelines and outcomes also recorded.

2.13. Strategies be put in place to slow the progression of chronic illnesses, particularly in the younger cohort.

2.14. Conduct a clinical review of BMI across the whole Achieve cohort including practices around meal choices, food preparation, diet, and physical activity.

2.15. The service needs to be flexible and adapt to the changing needs of clients, for example as they age and or develop dementia, with different health, behaviour and support needs.

2.16. Recognise that many clients have complex health needs and require ongoing nurse-led care and support. Invest in nurses beyond the two-year period and provide support for their ongoing professional development.

2.17. Consider that many of the nursing staff are themselves ageing and that a new generation of highly skilled nursing staff will be needed in the years ahead.