Living with Disability
RESEARCH CENTRE
Supporting inclusion of people with cognitive disabilities

Developing and maintaining person centred active support: A demonstration project in supported accommodation for people with neurotrauma
Final Report

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We would like to thank all the staff at all levels of the organisations that participated and the service users for allowing us to come into your homes. We acknowledge the contribution of the staff from the Living with Disability Research centre who contributed to the data collection, Lincoln Humphreys, Samuel Murray, Emma Caruana, and to the training, Silvia Warren and Lisa Hamilton.

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Executive Summary

The consistent use of Active Support by staff in supported accommodation services has been shown to lead to better quality of life outcomes for people with intellectual disability regardless of the level of disability (Bigby & Beadle-Brown, 2016). Active Support gives prominence to staff enabling service users to be engaged in meaningful activity and social relationships. It also provides the foundations for positive behaviour support. Although, some supported accommodation services include both people with intellectual disability and neurotrauma, research has not investigated staff use of Active Support in working with people with neurotrauma or issues associated with its implementation.

This project aimed to explore the applicability of Active Support in supported accommodation services for people with neurotrauma, and the effectiveness of this model of staff practice in improving quality of life outcomes for this group. It is an initial step in building an evidence base about the types of staff practices, team work, and practice leadership that contribute to good quality of life outcomes for people with neurotrauma living in supported accommodation. The key research questions were, 1) Is Active Support applicable as a staff practice with people with high and complex needs following neurotrauma? 2) Can Active Support be implemented in supported accommodation services for people with high and complex needs following neurotrauma? 3) What factors influence the adoption and embedding of Active Support in these settings?

This exploratory study used mixed methods to collect data about the quality of staff practice and service user outcomes before and after staff were trained in Active Support, and the perceptions of service users, family members, staff and managers about implementation of Active Support. It was conducted in three supported accommodation services in metropolitan Melbourne for people with high and complex needs associated with neurotrauma. The measures of service user engagement, quality of staff support and practice leadership were similar to those used in previous studies of Active Support. These rely primarily on observation using momentary time sampling techniques (see Bigby et al., 2017). Data were collected pre-training (T1) and at 3 months (T2), 12 months (T3) and 18 months (T4) post-training. After completion of the observational data collection, open ended semi structured interviews were conducted with staff, frontline managers, service users and a family member, in two of the three services to gather data about experiences of implementing Active Support.

The quantitative observational data did not show a clear pattern of increased quality of support (i.e. use of Active Support) or improved service user outcomes (engagement) following training in Active Support. One service showed a steady increase in levels of service use engagement from T1-T3 with a decline at T4, and another showed a sharp drop on this measure between T1-T2 followed by a sharp increase at T3. The range of scores in each service was wide, indicating substantial differences between engagement levels of individual service users – some did very little whilst others were more fully engaged in social and/or non-social activities. The levels of challenging behaviour were low in all three services. The results indicate that service users are mainly engaged in simple, solitary leisure activities, such as watching TV, reading, or using iPads and have low levels of engagement in simple household tasks such as laying tables or putting laundry away, or in more complex
tasks such as cooking that involved use of gas or electrical equipment. The data also shows low levels of staff contact and assistance from staff, and non-significant variations in practice quality over time that did not appear to follow a discernible pattern. In the third service unlike the other two, the percentage of time service users spent in social activity remained similar between T1-T3, and the percentage of time in non-social activity increased from 61% to 70% between T1-T3. This suggests some change of support practice occurred over time.

The qualitative data illustrated examples of good Active Support. There was strong support for the adoption of Active Support from staff, managers, service users and the family member interviewed. They highlighted some of the problems with existing staff practices, and the positive changes for services users and to staff practice that had occurred with the introduction of Active Support. There was a strong sense that Active Support meant that service users were encouraged to do many more things for themselves and that staff were standing back much more. A range of obstacles to the implementation of Active Support were identified, many of which had been identified in previous studies with people with intellectual disabilities; weak practice leadership by front line managers and lack of support from senior staff, staff resistance and limited understanding of Active Support, difficulties ensuring continued staff competence in Active Support given turnover of staff resulting from an organisational restructure. Other implementation difficulties were specific to services for people with neurotrauma, such as a stronger medical rather than support paradigm, more extensive involvement of Allied Health professionals as part of the support team for individuals, and differing support needs of some people with neurotrauma compared to people with intellectual disability. These latter factors suggest some of the adaptations that may be required to successfully implement Active Support in these services.

The study has provided evidence about the viability of implementing Active Support as a preferred practice for front line staff in supported accommodation services for people with neurotrauma, and identified the need to devise and support robust implementation plans if practice is to be embedded in services. These must, at a minimum involve;

- adaptation training materials to illustrate possibilities of Active Support for people with neurotrauma;
- leadership by senior and front line managers to reinforce and reward changed practice;
- class room training and hands on mentoring for all direct support and front line managers
- strengthening of practice leadership (coaching, modelling, team work, supervision and focus on direct practice) by front line managers;
- involvement of the Allied Health professionals who form part of the support team for each individual in the service.

It will be important that research continue to be conducted on the implementation and outcomes of Active Support for people with neurotrauma. This will ensure that further evidence is available to demonstrate the quality of life benefits to service users in order to inform commissioning and funding of services, as well as guide organisations on ways to embed good Active Support practice in their day to day work.
Background

Quality of life is widely used as a key indicator of service outcomes for people with disability (Schalock & Alonso, 2002). For people with high and complex needs, engagement in meaningful activity and social relationships is the way that many aspects of quality of life are realised. For example, independence and personal development are only possible if people participate in activities that broaden their experiences; interpersonal relations and social inclusion depend on interacting with other people; and physical health depends on lifestyle and activity (Beadle-Brown, 2006; Mansell & Beadle-Brown, 2012; Robertson et al. 2000).

This project explores how knowledge about the nature of good quality staff support in the everyday lives of people with intellectual disability may be adapted to inform the practice of support workers in supported accommodation services for people with neurotrauma. A large body of research in the field of intellectual disability has shown that the design (size and type) of supported accommodation and level of resources (particularly staffing) are necessary but not sufficient conditions for good quality of life outcomes (Bigby & Beadle-Brown, 2016). The two other consistently identified variables that impact on service user outcomes are the service user’s degree of impairment and staff practices, defined as the nature and quality of support provided on a day-to-day basis by frontline staff (Bigby & Beadle-Brown, 2016; Mansell & Beadle-Brown, 2012). Research indicates significant variability in the quality of staff practice and service user outcomes in services with similar levels of resources, both within and between organisations (Bigby, Bould & Beadle-Brown, 2017).

There is substantial evidence that frontline staff practice, based on Person Centred Active Support (Active Support), leads to better quality of life outcomes for people with intellectual disability regardless of the level of disability (Bigby & Beadle-Brown, 2016). Active Support gives prominence to staff enabling service users to be engaged in meaningful activity and social relationships. It also provides the foundations for positive behaviour support. Active Support is not something that is scheduled for set times or with particular service users; it is a way of working for support staff that is applicable at all times with all service users. As an evidence based practice, demonstrated to lead to better quality of life outcomes, Active Support has been difficult to embed in disability support services. A longitudinal study investigating the organisational factors associated with consistently good staff practice in supported accommodation for people with intellectual disabilities in
Australia has shown an association between good levels of Active Support and strong frontline practice leadership, training and hands-on mentoring in Active Support, and aspects of organisational culture (Bigby et al, 2017).

Reflecting the past trajectory in services for people with intellectual disability, there is increasing investment in the establishment of supported accommodation services for Transport Accident Commission (TAC) clients and others with high and complex needs as a result of neurotrauma. The applicability of Active Support to staff practices in supported accommodation services for this group of people has not been explored. Despite the significant body of work on professional rehabilitation practice with people who have experienced neurotrauma to increase their functional capacity and levels of independence, little research has investigated their everyday lives and quality of support in supported accommodation services; either staff practices or service user outcomes. As a consequence, there is a dearth of practice wisdom and research evidence to guide the practice of disability support workers in supported accommodation services for people with neurotrauma or the training and development of staff teams. A market research report for the TAC on traditional accommodation and support services indicated that, “in [TAC-funded] shared supported accommodation, the care was more passive i.e. it was often shared and the client has little or no control” (Huggett & McDonald, 2011, p.7). This is similar to practice found in services for people with intellectual disability where Active Support is not practiced. There is a danger that staff in newer supported accommodation models, such as Residential Independence Pty Ltd (RIPL) will simply replicate traditional ‘care’ practices, which will undermine broader aims, unless attention is focussed from the outset on an enabling approach to practice that emphasises facilitative support.

This project aimed to explore for the first time, the applicability of Active Support in supported accommodation services for people with neurotrauma, and the effectiveness of this model of staff practice in improving quality of life outcomes for this group. It is an initial step in building an evidence base about the types of staff practices, team work, and practice leadership that contribute to good quality of life outcomes for people with neurotrauma living in supported accommodation.

The key research questions were, 1) Is Active Support applicable as a staff practice with people with high and complex needs following neurotrauma, 2) Can Active Support be implemented in supported accommodation services for people with high and complex needs
following neurotrauma. 3) What factors influence the adoption and embedding of Active Support in these settings?

**Design and Method**

The study was exploratory and used mixed methods to collect data about the quality of staff practice and service user outcomes before and after staff were trained in Active Support, and the perceptions of service users, family members, staff and managers about implementation of Active Support. It was conducted in three supported accommodation services in metropolitan Melbourne for people with high and complex needs associated with neurotrauma. The measures of service user engagement, quality of staff support and practice leadership were similar to those used in previous studies of Active Support. These rely primarily on observation using momentary time sampling techniques (see Bigby et al., 2017). Data were collected pre-training (T1) and at 3 months (T2), 12 months (T3) and 18 months (T4) post-training. After completion of the observational data collection, open ended semi structured interviews were conducted with staff, frontline managers, service users and a family member, in two of the three services to gather data about experiences of implementing Active Support.

A one day interactive training workshop about Active Support was delivered to each staff team of direct support workers and their frontline manager. The workshop was based on materials adapted from Active Support training for staff working predominantly with people with intellectual disabilities (Every Moment has Potential) and designed with support of the second author who is experienced in working with people with neurotrauma. The workshops were delivered by an experienced practitioner/trainer who had worked in supported accommodation services that included both people with intellectual disability and neurotrauma. Each workshop was followed by in situ mentoring with the frontline manager and direct support workers whilst they worked on shift. Mentoring was originally planned to include one session for each participating staff member, but additional visits were scheduled notionally at fortnightly intervals as it became evident that due to staff turnover and structural staffing changes in services, some support workers and frontline managers had not participated in the training workshop. The number of mentoring visits varied for each service and were dependant on the willingness and availability of the frontline manager to engage in this activity. Many sessions were cancelled at short notice due to operational issues.
Measures

A modified battery of reliable and validated measures was drawn from prior studies of Active Support (Bigby et al., 2017) together with a semi structured interview schedule designed for this study.

Engagement in Meaningful Activities and Relationships. This observational measure was used to collect data on service users’ engagement in meaningful activity and relationships (EMAC-R) (Mansell & Beadle-Brown, 2005). Observations were carried out in each service and consenting service users were observed in rotating 5-min blocks during a two-hour period. Observations were usually between 1600 hours and 1800 hours, which is a period with many opportunities for participation in activity (Mansell & Beadle-Brown, 2011). At 1 min intervals, the researcher coded the activities the service users were engaged in, using three broad activity categories: social activity (interacting with others – talking to, showing, sharing information, listening and paying attention to someone speaking or interacting with them), non-social activity (any task or activity that was meaningful in that it promoted the person’s quality of life in some way, including self-care, leisure, audio-visual, household tasks and work activities), and unclear non-social activity (activity for people with profound disability where staff are providing hand-over-hand assistance, but it is unclear if the person is engaged). The researcher also coded two types of contact from staff; either assistance by staff or other people to engage in meaningful activity and relationships, or other contact from staff or other people that was not assistance (e.g., pushing someone’s wheelchair, giving medication). Four types of challenging behaviour, if present, were also coded; self-stimulatory, self-injurious, aggressive or destructive and other challenging behaviour (i.e. inappropriate sounds, inappropriate social approaches).

None of these categories are mutually exclusive in that service users could be doing more than one behaviour at a time. However, at each time point, the same behaviour could only be coded once. If none of the three types of activity occurred (i.e. no meaningful activity, no contact and no challenging behaviour), then the researcher recorded ‘none’. Researchers did not follow service users into bathrooms or observe personal care. If the researcher missed the observation for any reason, they coded ‘missed’. Percentage of time spent in each activity was calculated to take into account missed observations, and time spent in either social, non-social or unclear non-social activities were combined to measure levels of engagement over the two-hour period.
Active Support Measure (ASM). The ASM was used as an index of the quality of staff support. It has 15 items relating to the opportunities for involvement and the skills with which staff provided and supported those opportunities. Each item was scored on a scale of 0 (poor, inconsistent support/performance) to 3 (good, consistent support/performance) and is based on the researcher’s overall judgement of each item and completed at the end of the two-hour observation. A percentage of the maximum possible score on the ASM (45) was calculated for each service user observed. A score of 66.66% or above indicates good active support (Mansell & Beadle-Brown, 2012).

Observed Measure of Practice Leadership (Beadle-Brown, Bigby & Bould, 2016). This measure was used to collect data on the quality of practice leadership provided by frontline managers, and involved an additional visit to each service. The measure is completed following an interview (approximately 1 h) with the frontline manager of each service, a short observation of their work and review of some of the paperwork associated with practice leadership such as staff allocation, minutes of team meetings and minutes of supervision. All interviews were digitally recorded, and detailed field notes were written as soon as possible after each visit. After completion of the visit the researcher scored the five elements (see Table 6) of practice leadership on a 5-point rating scale (with 1 being no or almost no evidence of the element being in place to 5 being excellent – could not really improve on this element). An overall mean score of above 4 represents strong practice leadership on most elements, a score between 2 and 4 represents mixed practice leadership, and a score below 2, represents consistently weak practice leadership.

Client Characteristics. A measure of service user needs and characteristics was obtained by questionnaires completed by a staff member who knew each service user well. These questionnaires included the short form of the Adaptive Behavior Scale (SABS) Part 1 (Hatton et al., 2001), the Quality of Social Impairment question from the Schedule of Handicaps Behaviours and Skills (HBS) (Wing & Gould, 1978), and the Overt Behaviour Scale (OBS) (Kelly et al., 2006), which measures nine categories of challenging behaviour. Additional questions related to gender, date of birth and other disabilities present. The reliability and validity of the ABS (from which the SABS was drawn), the HBS and the OBS have been studied and reported as acceptable by their authors. The full–scale score for Part 1 of the Adaptive Behaviour Scale which is presented in the report was estimated from the Short Adaptive Behaviour Scale using the formula provided in Hatton et al. (2001).
Interviews semi structured. The interview schedule for staff (support workers, frontline managers and senior managers) consisted of questions about their role in relation to the service, and what a typical day working in the service might look like (or in the case of senior managers a typical week of managing the service). The researcher also asked about their experiences of introducing Active Support into the service/s (or organisation) in which they work, as well as the difficulties and/or challenges they had experienced, and whether they believed this way of working had made a difference to the lives of the people they support.

For service users and family members the researcher asked questions about the quality of support provided at the supported accommodation service, whether they were aware that Active Support had been introduced into the service, and whether this way of working has made any difference to the way staff are working.

Recruitment

Organisations known by the chief investigators, that provided supported accommodation services to TAC clients or other service users with neurotrauma were invited to participate in the study. Two organisations, each managing a number of services agreed to participate, and staff and service users from three services, drawn from two organisations agreed to participate.

The recruitment process was very protracted and as a result the study was conducted over a longer period than originally anticipated (mid 2015 – mid 2017). Several organisations initially agreed to participate but after a significant period of negotiation withdrew. One of the participating organisations, withdrew from the study after the T3 data collection, precluding collection of qualitative data about implementation. After a long period of negotiation, this organisation had also declined to agree to a second service participating in the study. Table 1 shows the dates of data collection for each participating service.

The study was approved by the La Trobe Human Ethics Committee and all participants gave informed consent. To ensure confidentiality none of the organisations involved in the study are identified by name. The two non-government organisations are referred to as NGO 43 and NGO 30 respectively and the for profit organisation as FP.
Table 1. Timing of intervention and data collection

<table>
<thead>
<tr>
<th>Service</th>
<th>T1</th>
<th>T2</th>
<th>T3</th>
<th>T4</th>
</tr>
</thead>
<tbody>
<tr>
<td>NGO 43</td>
<td>09/2016</td>
<td>10/2016</td>
<td>12/2016</td>
<td>09/2017</td>
</tr>
<tr>
<td></td>
<td>0 mentoring sessions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NGO 39</td>
<td>06/2015</td>
<td>06/2015</td>
<td>09/2015</td>
<td>07/2016</td>
</tr>
<tr>
<td></td>
<td>14 mentoring sessions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FP</td>
<td>12/2015</td>
<td>05/2016</td>
<td>08/2016</td>
<td>12/2016</td>
</tr>
<tr>
<td></td>
<td>8 mentoring sessions</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Analysis**

The quantitative data was entered into SPSS and descriptive statistics are presented for each service as a whole for each time point.

**Settings and Participants**

**Services**

One of the organisations was a large non-government service providing a broad cross section of disability support services to various groups of people with disabilities. The organisation had been progressively training its supported accommodation staff in Active Support in collaboration with La Trobe University since January 2015, and so already had familiarity with this practice. Two services participated from this organisation. NGO 43 was a new build, designed specifically for people with neurotrauma who also had a physical disability. It was modern in its appearance, both inside and out. NGO 39 was an older home (circa 1970's), but the interior had been modernised and there were photos and other artefacts belonging to the service users throughout the house giving it a homely feel. The second organisation was a for profit provider and service FP which participated from this organisation was larger than NGO 43 and NGO 39. It was home to eleven service users, of various ages and disabilities, however they all had a neurotrauma, and as expected for a large congregate facility, was quite institutional in its overall appearance and akin to a nursing home style rehabilitation facility.
Interviewees

Ten support workers, two frontline managers, four service users, split evenly between the two services from the NGO organisation were interviewed. In addition, a senior manager with responsibility for both services and a family member of a service user in NGO 39 was interviewed. Interviews lasted between 16 and 53 minutes. They were digitally recorded and transcribed. Interviews were analysed inductively using a constant comparative method. Data were coded by topic, and then into progressively more abstract categories.

Service users

Service users who gave consent to participate in the study were observed during the two hour visit to each service. The service users participating in each service at each data collection point, and their characteristics are shown in Table 2. As shown in the table, the number of consenting participants varied over time, due to service user movement (people leaving and/or new people moving into a service) and number of service users home at the time of data collection. All the service user had high and complex needs secondary to an acquired neurological injury.

As Table 2 shows the support needs of services users (based on their adaptive behaviour scores) in each of three services differed. Service users in NGO 43 had much lower support needs than those in NGO 39, and all have scores of less than 151, which has been used as a benchmark for a severe level of disability and has been shown to differentiate samples in terms of outcomes and the quality of support (Mansell, Beadle-Brown & Bigby, 2013; Beadle-Brown et al. 2015). The group of service users included at each data point differed in NGO 39 and FP. Notably, service users in FP at T2 and T3 had much higher support needs and thus were more likely to require support to be engaged than those at T1.
Table 2. Characteristics of the service users across the three services at each time point

<table>
<thead>
<tr>
<th></th>
<th>NGO 43</th>
<th>NGO 39</th>
<th>FP</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T1 – T3 (n=3)</td>
<td>T1 &amp; T2 (n=4)</td>
<td>T3 &amp; T4 (n=2)</td>
</tr>
<tr>
<td>Average age (range)</td>
<td>48 (42-53)</td>
<td>47 (34-57)</td>
<td>46 (34-57)</td>
</tr>
<tr>
<td>Percentage male</td>
<td>67%</td>
<td>75%</td>
<td>50%</td>
</tr>
<tr>
<td>Mean estimated adaptive behaviour score (range)</td>
<td>177 (152-206)</td>
<td>115 (81-149)</td>
<td>112 (81-142)</td>
</tr>
<tr>
<td>Overt Behaviour Scale (range)</td>
<td>26 (21-31)</td>
<td>17 (5-32)</td>
<td>9 (5-13)</td>
</tr>
<tr>
<td>Percentage with a physical impairment</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Percent with epilepsy</td>
<td>33%</td>
<td>25%</td>
<td>0%</td>
</tr>
<tr>
<td>Percent with visual impairment</td>
<td>33%</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>Percent with hearing impairment</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Percent with mental health problems</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Percentage socially impaired</td>
<td>33%</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>Percentage non-verbal</td>
<td>0%</td>
<td>25%</td>
<td>50%</td>
</tr>
</tbody>
</table>

**Findings**

*Service User Outcomes*

Tables 3a and 3b show the overall level of engagement of service users and the percentage of time spent in different forms of activity, as observed using the EMAC-R. Overall these data show a steady increase in levels of engagement in NGO 39 from T1-T3 with a decline at T4, a sharp drop in NGO 43 between T1-T2 followed by a sharp increase at T3, and a slight drop in FP between T1-T3. The range of scores in each service was wide, indicating substantial
differences between engagement levels of individual service users – some did very little whilst others were more fully engaged in social and/or non-social activities. The levels of challenging behaviour were low in all three services.

More detailed inspection of the data shows that in NGO 43 engagement in all types of activity declined between T1-T2 other than non-social leisure activity, and at T3, with the exception of non-social leisure activity (3% T3 vs. 9% T2), engagement in all types of activity increased. In NGO 39, where service users had higher support needs, the overall increase in engagement between T1-T3 was mainly accounted for by increased non-social activity (AV or leisure). This result indicates that service users were mainly engaged in simple, solitary leisure activities, such as watching TV, reading, or using iPads. The data suggests low levels of engagement in simple household tasks such as laying tables or putting laundry away, or in more complex tasks such as cooking that involved use of gas or electrical equipment.

In FP, unlike the other two services, the percentage of time spent in social activity remained similar between T1-T3, and the minimum increased from 0 to 3% of the time. The percentage of time in non-social activity in this service, increased from 61% to 70% between T1-T3. This suggests some change of support practice occurred as, notably, the sample of service users in FP had higher support needs at T3 than T1 and would be more likely to require staff support to be engaged. The range of scores also changed from T1-T3; the minimum for non-social activity increased from 33% to 40%. Most of the increase in non-social activity in this service was in solitary leisure activities such as watching TV or using iPads.
<table>
<thead>
<tr>
<th>Time Spent Engaged</th>
<th>T1 (n=3)</th>
<th>NGO 43 (n=3)</th>
<th>T3 (n=4)</th>
<th>T1 (n=4)</th>
<th>NGO 39 (n=2)</th>
<th>T3 (n=2)</th>
<th>T4 (n=4)</th>
<th>T1 (n=4)</th>
<th>FP (n=4)</th>
<th>T3 (n=4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage engaged less than 5%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Percentage engaged more than 50% of the time</td>
<td>67%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>50%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Time spent in social activity</td>
<td>35% (17-51)</td>
<td>11% (5-14)</td>
<td>17% (6-26)</td>
<td>13% (0-25)</td>
<td>16% (5-33)</td>
<td>2% (0-4)</td>
<td>1% (0-2)</td>
<td>24% (0-40)</td>
<td>21% (0-54)</td>
<td>24% (3-48)</td>
</tr>
<tr>
<td>Time spent in non-social activity</td>
<td>35% (26-45)</td>
<td>29% (21-36)</td>
<td>56% (35-64)</td>
<td>54% (32-83)</td>
<td>60% (33-90)</td>
<td>83% (66-100)</td>
<td>56% (33-78)</td>
<td>61% (33-90)</td>
<td>70% (49-100)</td>
<td>70% (40-88)</td>
</tr>
<tr>
<td>Self-Care</td>
<td>5% (0-9)</td>
<td>9% (3-16)</td>
<td>11% (3-20)</td>
<td>16% (0-28)</td>
<td>7% (3-13)</td>
<td>15% (12-19)</td>
<td>18% (17-18)</td>
<td>19% (0-33)</td>
<td>19% (0-14)</td>
<td>5% (0-10)</td>
</tr>
<tr>
<td>Simple</td>
<td>4% (0-7)</td>
<td>0% (0-0)</td>
<td>16% (13-20)</td>
<td>1% (0-6)</td>
<td>1% (0-3)</td>
<td>1% (0-1)</td>
<td>0% (0-0)</td>
<td>6% (0-0)</td>
<td>5% (0-9)</td>
<td>7% (0-28)</td>
</tr>
<tr>
<td>Complex</td>
<td>1% (0-2)</td>
<td>0% (0-0)</td>
<td>5% (0-9)</td>
<td>1% (0-4)</td>
<td>0% (0-0)</td>
<td>0% (0-0)</td>
<td>0% (0-0)</td>
<td>0% (0-0)</td>
<td>4% (0-13)</td>
<td>2% (0-9)</td>
</tr>
<tr>
<td>Audio Visual</td>
<td>22% (9-33)</td>
<td>13% (0-29)</td>
<td>22% (13-29)</td>
<td>24% (0-48)</td>
<td>39% (7-87)</td>
<td>40% (0-80)</td>
<td>28% (0-57)</td>
<td>30% (0-85)</td>
<td>53% (0-100)</td>
<td>45% (0-88)</td>
</tr>
<tr>
<td>Leisure</td>
<td>2% (0-7)</td>
<td>9% (0-26)</td>
<td>3% (0-6)</td>
<td>11% (0-31)</td>
<td>14% (0-35)</td>
<td>27% (8-46)</td>
<td>10% (3-17)</td>
<td>10% (0-39)</td>
<td>10% (0-29)</td>
<td>16% (0-60)</td>
</tr>
</tbody>
</table>
### Table 3b. Mean (and range) time spent disengaged

<table>
<thead>
<tr>
<th></th>
<th>NGO 43</th>
<th>NGO 39</th>
<th>FP</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T1 (n=3)</td>
<td>T2 (n=3)</td>
<td>T3 (n=4)</td>
</tr>
<tr>
<td>Mean percentage of time people spent disengaged</td>
<td>32%</td>
<td>61%</td>
<td>28%</td>
</tr>
<tr>
<td><strong>Minutes per hour disengaged</strong></td>
<td>19</td>
<td>36</td>
<td>17</td>
</tr>
<tr>
<td>Percentage of time spent in…</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-stimulating behaviour</td>
<td>15%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>(0-44)</td>
<td>(0-0)</td>
<td>(0-0)</td>
<td>(0-0)</td>
</tr>
<tr>
<td>Self-injurious behaviour</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>(0-0)</td>
<td>(0-0)</td>
<td>(0-0)</td>
<td>(0-0)</td>
</tr>
<tr>
<td>Aggressive behaviour</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>(0-0)</td>
<td>(0-0)</td>
<td>(0-0)</td>
<td>(0-0)</td>
</tr>
<tr>
<td>Other challenging behaviour (e.g. repetitive or inappropriate behaviour)</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>(0-0)</td>
<td>(0-0)</td>
<td>(0-0)</td>
<td>(0-8)</td>
</tr>
</tbody>
</table>
Quality of staff support

Table 4 shows data on the quality of staff support, gauged by the percentage of time during which service users were observed using the EMAC-R to receive assistance or other contact from staff. These data show low levels of staff contact and assistance, and variations over time that do not appear to follow a discernible pattern. For example, in NGO 43, contact dropped from 23% to 3% between T1-T2, and increased slightly to 9% at T3, and assistance dropped from 6% at T1 to 0% and T2 and T3. In NGO 39 contact increased from 10% to 15% between T1-T2, then fell at T3 to 2%, and remained at the same low level at T4; assistance increased from 0% to 15% between T1-T2, then dropped to 0% for T3 and T4. In FP contact increased from 4% to 16% between T1-T2, and continued to increase to 18% at T3. Whereas assistance increased from 0% to 10% between T1-T2 but dropped to 4% at T3. As discussed in later sections organisational changes which involved significant upheaval of staff teams and changes in frontline managers captured in the qualitative data rather than the influence of training, help to explain the variations in quality of practice in the two NGO services.

Following somewhat similar patterns to staff contact and assistance, the quality of support measured by the ASM was also variable over time, but increased in two out of the three services. In NGO 39, there was an increase between T1-T4 from 40 to 46; and for FP, ASM scores also increased from 52 to 63 between T1-T3. In contrast, ASM scores for NGO 43 decreased between T1-T2 from 87 to 44, and despite an increase to T3, remained lower than the score at T1 (60 vs 87).

With the exception of NGO 43 at T1, where scores on the ASM were over the threshold for good Active Support (i.e., 66%), service users received mixed levels of Active Support (scores from 33% to 66%), with many opportunities to involve service users missed and a lack of consistency between staff and across time points evident. A closer inspection of scores on the 15 items in the ASM (see Table 5) indicates services scored relatively better on the items related to age appropriateness of activities, communication and interpersonal warmth.
Table 4. Quality of observed staff support – staff assistance, staff contact & Active Support measure

<table>
<thead>
<tr>
<th></th>
<th>NGO 43</th>
<th>NGO 39</th>
<th>FP</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T1 (n=3)</td>
<td>T2 (n=3)</td>
<td>T3 (n=3)</td>
</tr>
<tr>
<td>Time spent receiving contact from staff (range)</td>
<td>23% (6-35)</td>
<td>3% (0-6)</td>
<td>9% (0-18)</td>
</tr>
<tr>
<td>Converted into minutes per hour</td>
<td>14</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Percentage of service users not receiving any contact</td>
<td>0%</td>
<td>33%</td>
<td>33%</td>
</tr>
<tr>
<td>Percentage of service users receiving contact more than 20% of the time</td>
<td>67%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Time spent receiving assistance (range)</td>
<td>6% (0-15)</td>
<td>0% (0-0)</td>
<td>0% (0-0)</td>
</tr>
<tr>
<td>Converted into minutes per hour</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Percentage of service users not receiving any assistance</td>
<td>33%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Percentage of service receiving assistance more than 10% of the time</td>
<td>33%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>ASM Score (range)</td>
<td>87 (82-95)</td>
<td>44 (41-46)</td>
<td>60 (49-67)</td>
</tr>
<tr>
<td>Percentage ASM less than 33</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Percentage ASM more than 66</td>
<td>100%</td>
<td>0%</td>
<td>33%</td>
</tr>
</tbody>
</table>
Table 5. Quality of staff support, mean ratings on each item of the Active Support Measure

<table>
<thead>
<tr>
<th>Item</th>
<th>NGO 43</th>
<th>NGO 39</th>
<th>FP</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T1 (n=3)</td>
<td>T2 (n=3)</td>
<td>T3 (n=4)</td>
</tr>
<tr>
<td>Age appropriateness</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Real activities</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Choice</td>
<td>3</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Demands presented carefully</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Tasks analysed appropriately</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Sufficient staff contact</td>
<td>3</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Graded assistance</td>
<td>3</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Speech matches developmental level</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Staff notice and respond to client</td>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>communication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal warmth</td>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Differential reinforcement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(n=0)</td>
<td>(n=0)</td>
<td>(n=0)</td>
</tr>
<tr>
<td>Staff respond to challenging behaviour</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(n=0)</td>
<td>(n=0)</td>
<td>(n=0)</td>
</tr>
<tr>
<td>Staff work as a team</td>
<td>3</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Incidental teaching</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Written programmes in routine use</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Note. Each item is rated on a scale of 0 (poor, inconsistent support/performance) to 3 (good, consistent support/performance).
The field notes\textsuperscript{1} completed by researchers during and shortly after the two-hour observation illustrate some good examples of Active Support, but also the variable quality of staff support in these services.

\textit{Good Active Support and contact from staff}

Service user was supported using graded assistance to prepare afternoon tea of a toasted sandwich. The staff member got out the items the service user was unable to reach from his wheelchair (e.g., spreads in high up cupboard and fridge), and placed a small amount of each into small dishes so he was able to take all ingredients to the kitchen table and construct the sandwich with chosen ingredients. [NGO 43, T1].

The staff member asked the service user, “Do you want me to do some reading to you?” He replied, “Yes” and the staff member sat at the dining table with the service user and angled the car magazine so that he could see it, but also so the staff member could see it to read it aloud. As the staff member read the article, he commented to the service user about the article. For instance, the article described the effort and steps involved for a person to have his car painted red. The staff member said, “He likes red, doesn’t he?” and reading about the specification of a car and commented “That’s massive, isn’t it?” [NGO 39, T1].

The staff member provided good hand-over-hand support that enabled the service user to cut carrots. He used other strategies to support engagement in decisions or other aspects of meal preparation, saying for example “should we put extra curry powder in it?” “can you smell it?” as he held items up to the service users nose; and supported him to run his fingers through the rice that was about to be measured into a cup, placing things in bowls, and wiping down his wheelchair tray at the end. Later on, the same service user was supported to hold the two ends of a bedsheet whilst the staff member folded it. [FP, T2].

The service user was supported to blend some of the evening meal for himself and others who required a modified diet. A staff member brought the blender to him and placed it on his wheelchair tray, and then placed another portable table next to him so that all the items were easily accessible. Then, the staff

\textsuperscript{1} Pseudonyms have throughout the qualitative data in order to ensure the deidentification of participants.
member used a combination of verbal prompts and praise, physical support and hand-over-hand support, to enable the service user to control the blender and scoop from the bowl to the blender hopper. [FP T2].

Service user 1 needed minimal support to take part in the cooking, and did parts of it himself without any support at all. Service user 2 was supported, co-actively to eat an afternoon snack. The staff member attached an assistive device to his arm, designed by an OT, and then gave some hand-over-hand assistance. On a few occasions, the staff member gave him the opportunity to eat completely independently (with just the device to assist him). [FP, T3]. There were only a few examples of appropriate other staff contact or support for choice making,

When the service user went to his room and started watching TV, the staff member came to check and see if everything was okay due to the very loud noise of the TV coming from his room and uncertainty about what may be going on. [NGO 43, T1].

The staff member asked the service user “Do you want to watch TV in the lounge room or your bedroom?” and “Do you want to watch this TV show or a different one?” [NGO 39, T2].

Service user was asked if he wanted to stay in the kitchen area or go and watch TV. He chose to stay and this was respected. [FP, T2].

There were examples of staff interacting with service users in a friendly and warm manner. For example,

The staff member engaged in a lot of social interaction with all the service users throughout the observation, much of which was light-hearted banter and conversation. [NGO 43, T1].

Several times the staff member asked questions or explained things to the service user. In one instance, he repeated a joke that was said on the news and asked the service user if he got it. [NGO 39, T1].

Examples of poor quality support

There were numerous examples of poor quality support and missed opportunities to enable service users to be engaged. For example,
Staff pointed out that service user 1 was rostered to do dinner preparation that night, however he said he did not want to be involved, so the staff members did all of the required tasks despite three other service users at home who could have been asked if they wished to take part. [NGO 43, T1].

At the start of the observation a staff member approached the researcher and explained that dinner had been cooked earlier in the day because “…it gets so busy in the afternoon…” For most of the first part of the observation both staff members sat around talking or were in the office. Throughout the observation staff were observed alone folding laundry, cooking the evening meal, emptying rubbish bins, completing paperwork, making beds, and general tidying. [NGO 39, T3].

One service user spent the duration of the observation sitting in his wheelchair in the middle of the walkway area between the front door, kitchen and staff office. He spent some time looking at pictures and videos on his iPad, and staff walked around him without attempting to engage him in the dinner preparation or social interactions that were happening in the kitchen. [FP T1].

Little staff contact was observed. Most service users were able to engage themselves in activities such as playing on iPads, and watching TV, and were often ignored by staff. For example,

Staff were engaged with each other, in the office, or both staff were with service user 1 leaving service user 2 by himself. Service user 2 tried to engage the researcher a couple of times in social chat and seemed keen for some social contact but was not offered any. He called out three times to staff, but was ignored each time. [NGO 39, T3].

There were many examples throughout the observations of service users having low levels of choice, staff members adopting a controlling stance, and being disrespectful. For example,

The service user asked one of the two staff members who were preparing dinner to scan a receipt for him, sounding quite anxious about it. The staff member replied that he was too busy preparing dinner and that the service user needed to wait until after 9pm for staff to attend to that request. It was about 5:30pm at this point. Ten minutes later, both staff were still complaining to each other about how demanding this service user could be. [NGO 39, T3].
The service user started to type something out on his communication device, “I don’t want…” The staff member came over as it was read out by the electronic device. Instead of asking more, or waiting to see what was to be typed next, the staff member said, “...keep typing and I’ll come back...” He did not return for 39 minutes, and then went to get the service user’s cup and asked “can I get you a drink?” The original message was not mentioned again. [NGO 39, T4].

One of the service users asked the frontline manager, “How are you today?” The manager replied “Shocking, just shocking...you ask me that everyday so I thought I would swap it around”. The manager then went into the staff room and said to no one in particular “And then you ask me again and again and again and again and again and again”. [NGO 39, T1].

Service user 1 spent the entire observation doing nothing aside from occasionally talking to service user 2. A staff member came over to him and said, in a stern voice, “hurry up with that drink, its stone cold now”, and then walked way. The service user whispered as he walked away, “that’s how I like it”. [NGO 43, T2].

Two staff members were talking for a few minutes about service user 1’s fluid intake and how he really needed to be drinking a lot more water. Neither included the service user in the conversation despite standing in front of him. Service user 2 was asked whether he wanted to watch TV, and he replied, “I’d rather use my iPad”, to which the staff member said, “how about you say please first?” The service user paused, asked for his iPad again, and staff member said “where’s the ‘please’?” [NGO 39, T3].

Shortly after the service user had been offered a choice to remain in the kitchen, he was wheeled into the lounge area without being offered any choice. Whilst this was happening, another service user entered the kitchen and asked if he could have another cigarette, to which the staff member replied immediately, “15 minutes...how about you help out in the kitchen instead? You like to eat, but never help out”. [FP, T2].

**Perceptions about Applicability and Implementation of Active Support**

Patterns in the observational data are reflected and explained by the analysis of the qualitative data from the semi structured interviews with staff, managers, service users (who were referred to as residents or clients by staff) and a family member. These data provide
insights into staff views about the applicability of active support in these settings, perceived benefit for service users and practice changes.

**Support for adoption of Active Support and practice change**

There was strong support for the adoption of Active Support from staff, managers, service users and the family member interviewed. They highlighted some of the problems with existing staff practices, and the positive changes for services users and to staff practice that had occurred with the introduction of Active Support. There was a strong sense that Active Support meant that service users were encouraged to do many more things for themselves and that staff were standing back much more. For example, one staff member talked about the benefits of Active Support for a young woman she supported,

> It’s helped her a lot, I think. She’s started to realise how much she can do for herself…So she can transfer out of bed independently now. And when she goes to the toilet, instead of needing some assistance, she’ll actually wipe herself. We just pull her pants up and down. Like we were doing everything for her…it’s given her more dignity as well…Yes, I do [think active support is a good idea], and it depends on the individual you’re working with. Like with Catherine again, good example, it’s been brilliant for her. She’s very self-aware, and it’s less us and more her. It’s taken stuff out of her – like we haven’t really pushed a lot of it. She’s come to realise or it’s awoken something in her. So I think it’s been really good. [Suzanne, staff, NGO 39].

Staff in both NGO services saw benefits in adopting Active Support,

> It seems a little bit more personal because you get to know each of the residents and their likes and dislikes. I don’t know, it’s just a bit more about them. [Alice, staff NGO 43].

> It’s almost like giving them back the control that they should have always had. [Nicole, staff, NGO 43].

> I think the clients could be involved in the making of dinner a lot more than they are…Where at the moment, they’re not being given the option. Madeline spends a lot of time of an afternoon sitting down – when she comes back from her outing, sitting down in her room watching TV, whereas she loves cooking. Why doesn’t she actually help cook dinner?” [Heather, staff, NGO 39].
Although, the quantitative observational data did not suggest major changes to staff practice had occurred, many of the staff interviewed drew attention to the way they thought support practice had changed to reflect Active Support, saying for example,

[Staff are making] more of an effort… they are doing more in their quiet times rather than just go “right every ones settled I’m sitting down for a cuppa”. [Grant, staff, NGO 39].

I think definitely we do try and stand back a bit more and encourage them to do more. Like there’s been a lot more, I think with the cooking…It’s been such a progress… we would actually be physically putting away all of the clothes for them. Whereas now we put away about half of them and they can do the other half. [Nicole, staff, NGO 43].

So this morning – I held the pot for him. I got him to put in the rice, put in the milk and stir it on the stove until it started boiling. [Annie, staff, NGO 43].

Staff are more involved in activities with the residents. We’ve actually got a box underneath in the office for craftwork and paintings. Some of the residents like to do paintings and we will organise a framework so they can give to family paintings in there, different craftwork as well…I think it’s more interactive with the residents than it was before. And it’s also the residents too, whether they want to get involved. [Beverley, staff, NGO 43].

I think because when it did start, we were consistent with everybody. And we weren’t, “You have to do this,” of course. So, it was a gradual change that happened. And as long as we attempted stuff with little bits and pieces with everybody – that’s what we tried to do…I have found with Active Support, it’s more kitchen-based. I think that’s where we get really the best results. [Suzanne, staff, NGO 43].

One support worker said that a resident had initially objected to the idea of Active Support, feeling that it was not culturally appropriate to be involved in household tasks, however her comments suggested the change of approach was appreciated by most service users,

At first none of the service users liked it, but I think they’ve all come around to it quite easily, and I think they all will enjoy it now. Kirk used to wait for the staff to come to start cooking, whereas now he just takes it upon himself and he starts cutting up the ginger and the garlic and he just does it because he knows where everything is and he knows that he can do it now. I think before he didn’t quite know or he didn’t
have the confidence that he could do it, and now he just starts and it’s kind of like Kirk has started cooking, we [staff] better get in there and you kind of come in and you kind of sit there and have a conversation with him while he’s cooking. Pretty much like you don’t have to do much for him any more at all. [Nicole, staff, NGO 43].

Service users themselves were also positive about the changed approach by staff, saying for example,

I think they [staff] have been encouraging more active support and for me to do more things myself, than the spoon feeding, you know?” (Kirk, SU, NGO 43).

Putting your clothes away. They [staff] started by putting them in my room. Now they’re putting them on a chair and I’ve got to take them back to my room, put them away. That’s a bit hard when you have trouble hanging things up. (Catherine, SU, NGO 43).

The family member who was interviewed grasped the idea of Active Support immediately, although he had not heard the term before. He was very positive about the ideas behind it, saying for example, that doing things in the kitchen could complement the hand exercises his daughter needed to do. He also talked about the importance of continually trying to offer choice and extend his daughter’s engagement, even if at times she said she didn’t want to do something. He said, “don’t give up it might work next time when she is not so tired”. His view was that staff could support his daughter to be more engaged at home, particularly in the time between scheduled appointments and activities,

Madeline knows, each day she’s getting up, and we know that she’s going to be involved in some activity…there’s still some down time here, when people could actually be engaging more with Madeline…I think, at times, Madeline can be just left to her own devices…whereas I think they could be more proactive, in terms of getting her to do things…I’m not too sure whether much happens, other than them doing a daily – you know the caring for Madeline, in terms of a catheter, or getting the meals organised for her, and that sort of thing. I’m not too sure whether much else happens sometimes…It depends who’s on. Because they vary a little bit, in terms of how much the staff want to be involved. [Father of service user, NGO 39].

*Inconsistent ‘hit and miss’ changes to practice*
The use of Active Support was characterised as ‘hit and miss’ by one staff member, and others suggested that the initial impetus to change practice had not been followed through. Their comments reflect the observational data that Active Support was in the early stages not a consistently used practice among all support staff,

No matter how much I keep hearing it, I guess it’s like sometimes things don’t sink in that well. We’ve tried to implement it in the house. We had training – we had Silvia here ages ago. I was here for that. But when it first started up, I think we were pretty vigilant. And now it’s hit and miss. It’s really inconsistent in the house… [Suzanne, staff, NGO 43].

I mean we try different things that we thought both Elliott and Madeline, maybe they could be – like getting mail out of the letterbox, and jokingly sort of say, “It’s your house. You can go get the mail; not me.” That lasted two days. [Grant, staff, NGO 39].

A lot of it just doesn’t happen…Just getting everyone on the same page pretty much. [Faith, staff, NGO 39].

Everyone went and did the one-day training and the team leaders [frontline managers] in the houses were supposed to come back, and it didn’t work…whether the team leaders didn’t understand that. I was one of them. We were the first ones to do it…So my understanding was very clear of what I had to do, but then when I moved from a team leader role in this house into a client engagement coordinator role in the respite facility, what I was applying here in the respite facility wasn’t being applied elsewhere, so I guess it was a lack of understanding of what the whole thing was about and how it was supposed to be delivered consistently is what I think is the biggest issue. [Fiona, staff, NGO 43].

**Difficulties Implementing Active Support**

Interviewees identified a range of obstacles to adopting Active Support. Some of these, are similar to those found in studies of intellectual disability services, such as the absence of strong practice leadership, staff turnover and the associated difficulties of ensuring all staff have training in Active Support, staff resistance to changing practice and misunderstandings about of the nature of Active Support. Other difficulties were more specific to services for people with neurotrauma, such as a stronger medical rather than support paradigm, more extensive involvement of Allied Health therapists as part of the support team for individuals, and differing support needs of some people with neurotrauma compared to people with
intellectual disability emphasising the importance of being person centred but also seeking advice from therapy professions about things such as hand-over-hand assistance. These latter factors suggest some of the adaptations that may be required to successfully implement Active Support in these services.

“We need someone to be a driver for this” – perceptions of weak practice leadership and support from senior staff

Active Support had been adopted across all supported accommodation services in the NGO with strong expressed support from the CEO and the general manager of client services. As the senior manager said,

It’s been driven from the highest level in the organisation…the CEO would know about it, but particularly the general manager of client services, she promotes Active Support very heavily, it’s something that the Learning and Development team knows about, our HR team knows about it, and it is appearing in things like job descriptions and training programs and so on and so forth.

Despite this all levels of staff, from this senior manager down felt that leaders in the organisation gave frontline staff little support with implementation of Active Support. The senior manager, while supportive of Active Support, expressed regret that he did not have time to support staff as most of his time was taken up troubleshooting difficult issues. He said, “I try to go along to team meetings as often as I can, but I just tend to get drawn towards houses and meetings when there are issues that need to be addressed”. Reflecting this, frontline staff and managers felt they rarely saw anyone from ‘head office’ and remarked on the absence of senior leaders. They also perceived that personal or health care were more highly valued by senior management than Active Support. They said for example,

We have our team leader [frontline manager] here, but we don’t really see anybody from head office. Occasionally they might come in”. [Beverley, staff, NGO 43].

Money is a big thing. Trying to get the funding…we just need this little bit of equipment, like the chopper thing. Who funds that and how to get the funding for that seems to be a sticking point for just about everything when you try and buy something new…it does become really hard if you’re then asking for a specialist bit of equipment that’s for the house – as opposed to one client …[Heather, staff, NGO 39].
The senior manager sent me a few emails regarding [the project] way back when you were starting all this. Forwarding things on, make sure it gets done, forwarding it on to the next person. Push it down the line…I’m not saying he doesn’t know or they don’t know what they’re talking about up there. They probably know quite a bit about it. But, as far as us knowing what they expect or whatever, I’m not really sure. I know what my line manager expects. But above that, just push it down, push it to the staff, the support workers. [Suzanne, staff, NGO 43].

The absence of support from frontline managers for practice change, through the elements of practice leadership, such as focus on quality of life, teamwork, reflection, coaching, modelling and supervision was a strong and consistent message from all levels of staff in the NGO. Talking about his frontline manager one staff member said,

I see him every now and again. But when he’s here, he’s here in this room [office]. So, he’s not observing…we believe he should be sitting out there and seeing a bit more. That way he can see what staff are doing, what they’re not doing, make suggestions even. Doesn’t have to be all the time. But as I said, when he comes, he sits in here. The door’s always open. But he can’t see – he might hear it a little bit. But I truly believe if he was sitting out there, he could see a bit more, and maybe some of the slacker staff would pick up…so they would turn around and do something with the guys rather than sit down and have a coffee watching television. But if he was out – I’m not saying it’s spying or anything. But just being in here. [Grant, staff, NGO 39].

The two frontline managers recognised the importance of their role in fostering good staff practice but complained about the way their positions were structured which meant they did not have time to focus on the things they saw as important to practice. As one said,

I guess my job should be coaching and supporting staff in delivering Active Support and many other facets of the job, but it hasn’t actually turned out that way to date. It’s more about administration side of things…my biggest frustration is I’m doing all this admin stuff rather than supporting and coaching staff to up-skill…that would be for people like me in my role to be actually doing my job rather than doing administration stuff. So that would be for me to be on the floor in and out of the houses at every hour of the day and weekends and stuff…because you pretty much pick out who’s been challenged by person centred active support in your staff, and being around to be able to monitor it and coach and address it in supervisions. But
right now, I have to do rostering, I have to do finance, I have to do maintenance. I have to do all that other stuff to keep things ticking along, and I think my biggest time-consumer is rostering…I’ve just got to have time to do it [supervise practice].

[Fiona, frontline manager, NGO 43].

The senior manager concurred that the organisational structure did not allow time for frontline managers to lead practice. He said,

So, the frontline manager is across three houses and a respite service. The thing with the respite service, it is just temporary because there’s just a bit of uncertainty to what’s going to happen to the respite service. But it’s clearly not a good situation. They’re just not there in the house often enough watching what staff are doing and so with that current structure in place I think that we’re going to really struggle to make any progress in Active Support. In fact, any groundwork we’ve made we will probably lose. [Ian, NGO senior manager].

The perceived inherent problems with the span of responsibility and focus on administration of the frontline manager positions and the negative impact on the exercise of good practice leadership, was compounded by changes of staff who held this position in NGO 39. The restructuring of frontline manager positons occurred in late 2015, very soon after the training had been conducted in this service. As a consequence, the frontline manager who had been involved in the classroom and in situ mentoring left and was replaced by a series of short term appointees over the following 18 months. As one staff member said about the frontline manager position,

We went through quite a long time of change, not having somebody permanently here – that was probably over six months, I suppose, that we didn’t have a leader in a lot of ways, a part-time leader, who was Fiona, who was doing her upmost to run too many places. And, she’s fantastic, she’s an amazing woman, and she is very much person centred, she’s amazing, so. [Researcher: Does she have an influence here, though?] No, unfortunately not, no because she was never here, she wasn’t here enough and things just cruised along as they always had, and no changes. And, then Darren arrived and it took him a long time to get to know what was happening, and how the place is. And yeah, I think now it’s starting to settle down finally, but it’s taken a while. Yeah, but there’s still a lot of things that could be done. [Faith, staff, NGO 39].

Staff resistance and limited understanding of Active Support
The semi structured interviews with staff indicated that some were resistant to Active Support, and did not have a strong grasp of the rationale, the potential beneficial effects of engagement for service users or how to translate ideas about Active Support into practice. One staff member for example, suggested that the service user who was most capable was the most important person to focus on as he had more chances of becoming independent. Staff talked about not having time for Active Support on top of the other work they had to do, and many clearly saw their primary role as the completion of household tasks, medical and personal care.

Sometimes, it gets a bit frustrating to have to do all that and then deliver Active Support over something really tiny. It’s not like making somebody lunch for five minutes would take away their independence completely. Because even us, who are abled bodied people, do stuff for others sometimes. It’s just a favour or – how can I put it? You’re just trying to get through the day…Yeah, you have to prioritise. If you can do something and then offer the Active Support later for something bigger; why not? Yeah. [Annie, staff, NGO 43].

In the morning, there’s three support workers on. A very busy time, showering, dressing, breakfast, meds, getting the rooms clean, getting the washing on, any soiled clothing, it’s very busy till 11 o’clock. It dies down between 11.00 and 11.30 but in the interim time between 11.00 and 11.30 we’re still getting washing coming through, so there’s folding and putting away. [Harper, staff, NGO 39].

We’ve got 1,001 things to do and we’re now trying to slot something else in there…one of the biggest things is the fact that it takes longer to get stuff done, which can be quite challenging when you’ve got taxi drivers turning up at 8:30 in the morning and stuff like that. You’ve got deadlines to meet for when a client needs to be ready to go out, and trying to fit in for them to do something for themselves. Even if it’s five minutes, that adds up when you’ve got four people…For example, Russell doesn’t make his own cup of coffee of a morning because there just isn’t the time for him to do it. [Heather, staff, NGO 39].

I would put medications over Active Support, that’s just the way I think. I think that’s life-changing medications. You muck up there – I would prefer to train someone in medications and how to look after them in their personal care routines, and then start on the Active Support stuff. That, to me, is something that will come last. So as we’ve had a lot of casual staff in rotating that, we haven’t focused a lot on that stuff,
because we’ve been busy making sure that the residents’ health and wellbeing is paramount. [Suzanne, staff, NGO 43].

One staff member talked primarily about Active Support as service users doing leisure activities such as craft or board games together,

When all the work is more or less done and time is low key and we might have half an hour that we can spend and supervise their game, because the minute one of the staff members walks away the game comes to a halt because intellectually there’s no prompting. What do you think you can make today? That spurs them on whereas otherwise I’d just be looking out into mid-air basically or saying I’m going to go and do my writing or Russell saying I want my iPad. Yes, that kind of thing. [Harper, staff, NGO 39].

Staff were risk averse and weak practice leadership meant that these issues and concerns had not been addressed with individuals,

It’s too dangerous for Russell to mop his floors. He can’t walk well enough to do it. But someone sitting in a wheelchair, vacuuming, I don’t see why not. Things like that. [Heather, staff, NGO 39].

The father of one of the service users very astutely pointed to the skills staff required to practice Active Support, saying,

So, I don’t think it does happen. So why not? I think it’s just easier and quicker just to do things the way they have been done. Involving Madeline, it might be tricky. Things might take more time. So, yeah, people take a bit of a short cut, just get the job done and tick that off, that’s done, and just take the easy way. [Father of service user, NGO 39].

Several staff recognised their need for more training, and this was also raised by the senior manager, but stronger leadership was required to take action on this need,

More training, on-the-job training to come out and help assist with the residents as well as the best way to approach them. I mean we try our best as support workers to get the person out there, but it always come back to it’s their choice. So maybe if they could come at a different approach to get that person out there in the community, I think that would be good”. [Beverley, staff, NGO 43].

We need another training session [laughs]. And then I think that would be – that would jog whoever was already here for the last one’s memory to help the new
people, but also new ideas, et cetera...I think it’s something like that to have a refresher course with – if it’s such a big thing that you want to implement, it needs to be – you’ve got to have some kind of refresher course for people. It’s such a new thing that’s been brought in to have…back when it started – they [senior managers] made sure that we were following through with it; sort of the driving force behind it, I guess. So, it wasn’t just left for us to figure out. We were being monitored and observed. So, we were actually doing it. And I think that’s why we were so consistent as well. [Suzanne, staff, NGO 43].

The senior manager also commented about the need for more training but had not taken a proactive stance to this,

I’m sure it’s [training] going to appear at some stage, it just needs to be organised. But you can’t just do the training one off, I think you need to do refresher training”.
[Ian, NGO senior manager].

**Weak observed practice leadership**

Data from the Observed Measure of Practice Leadership, reflected the comments from staff and managers about the weak practice leadership in the NGO services. Table 6 shows the low scores overall and on each of the elements of practice leadership across all three services. The frontline manager for each service at the time was included in the classroom based training and the follow up mentoring, but the turnover of staff meant those who subsequently held the position had not participated in these sessions. No specific training was given to frontline managers in the five elements of practice leadership. Due to the premature withdrawal of FP, the measure of practice leadership was not completed at T3.

As Table 6 shows although there was some improvement between T1-T3 for NGO 39 and NGO 43, practice leadership was low across all three services and all 5 elements. No service was rated as good or excellent (score of 4 or 5) on any of the elements of practice leadership.
The manager/house supervisor focuses, in all aspects of their work as manager, on the quality of life of service users and how well staff support this.

Allocating and organising staff to deliver support when and how service users need and want it.

Coaching staff to deliver better support by watching how staff support people, telling them what they are doing well and what needs to be improved and showing people how to provide better support.

Reviewing the quality of support provided by individual staff in regular one-to-one supervision and finding ways to help staff improve their support.

Reviewing how well the staff team is enabling people to engage in meaningful activity and relationships in regular team meetings and finding ways to improve it.

**Overall Score across 5 elements**

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<th>NGO 43 Baseline (n=1)</th>
<th>T3 (n=1)</th>
<th>NGO 39 Baseline (n=1)</th>
<th>T3 (n=1)</th>
<th>FP Baseline (n=1)</th>
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<tr>
<td>The manager/house supervisor focuses, in all aspects of their work as manager, on the quality of life of service users and how well staff support this.</td>
<td>2</td>
<td>2</td>
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<tr>
<td>Allocating and organising staff to deliver support when and how service users need and want it.</td>
<td>2</td>
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<tr>
<td>Coaching staff to deliver better support by watching how staff support people, telling them what they are doing well and what needs to be improved and showing people how to provide better support.</td>
<td>1</td>
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<tr>
<td>Reviewing the quality of support provided by individual staff in regular one-to-one supervision and finding ways to help staff improve their support.</td>
<td>1</td>
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<td>3</td>
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<tr>
<td>Reviewing how well the staff team is enabling people to engage in meaningful activity and relationships in regular team meetings and finding ways to improve it.</td>
<td>2</td>
<td>3</td>
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The data from field notes written by researchers and the interviews conducted with frontline managers as part of completing the measure help to explain the low scores on the Observed
Measure of Practice Leadership and reflects data from the semi structured interviews conducted with both staff and frontline managers at the end of the study.

One frontline manager had a very limited perception of his role and possibilities of enabling engagement or choice and control of service users, as well as displaying a disrespectful attitude towards services users,

Let’s face it we are nothing more than a bloody glorified B&B, we give them a bed and we feed them and make sure they’re clean, their day programmes do the rest…When asked if residents have choice, such as what to eat, he said “Oh God no, they’d just choose crap. And as for taking them to the supermarket, pppfftt forget it, Russell would grab every single packet of biscuits in the joint”. [NGO 39, T1].

This frontline manager perceived the service that he managed as being different from others managed by the organisation which had different funding structures and mix of service users,

We don’t do all the s%#t like they do in Departmental houses, they want us to do active support and all that crap, they even want us to do keyworker reports, we don’t even have f%$#in’ keyworkers!!” [NGO 39, T1].

Reflecting the semi structured interviews, frontline managers felt they did not have the opportunity to observe staff practice or to provide coaching. Rather they talked about relying on staff or service users to report what happened in the service,

I rely on other staff. That is my main way of finding out what is going on, I have spies. I can remember saying at one of the team meetings that I’m a big advocate for dobbing. [NGO 39, T1].

I walk around, and when I’m working on a shift I get feedback from the resident’s [about the support being provided]. [FP, T1].

Although the NGO had a standard format for supervision this was not being used, and supervision was irregular,

I’m talking to staff all the time, but we haven’t put it down on the formal side of supervision. We will sit down and do supervision with staff, every month …depending on what’s…like or every six weeks. It could even be over the phone. We do really need to get that up and running”. [NGO 39, T1].
Organisational expectations about staff supervision were lower in FP than the NGO and the frontline manager at FP was only expected to supervise the three more senior staff in the service. He said about supervision,

Hopefully every three months, and lasts about 30 minutes, or as needed if I think someone needs to be touched based with…where they think they need more training and assistance, how they think the house is running, how to improve their workload, getting feedback from them on how things are going…we also talk about their duties, or things they need to follow up, how we can improve that, or do they need to be shown how to do things”. [FP, T1].

Team meetings occurred irregularly in the NGO services but did not have a strong focus on staff practice and or service user outcomes. One frontline manager explained the problems with having staff meetings, “In this industry, pay is s%#t, people often have jobs elsewhere, making staff attendance at meetings problematic”. He went on to talk about the focus of meetings which the minutes confirmed were primarily concerned with service users’ personal needs such as continence and weight management and housework,

Mainly the house. What is going on in the house how staff are feeling about different things, has anybody got any problems, talk to us and we’ll hash it out…Today we’re talking about policies and OHS stuff…Like today there is a new handover procedure and we’ll go through that. [NGO 39, T1].

Team meetings were held only twice a year at the FP service, and the manager said,

We talk about how the house is running, incident completion how to document it, and everyone got a template on how to do it, but yeah, not sure what else off the top off my head. [FP, T1].

**Difficulties ensuring staff team competence in Active Support**

One of the challenges to adopting Active Support, and ensuring consistently good practice was ensuring that all team members understand the type of practice required and had opportunities for continuing development of their skills and support to practice in the way that is expected by the organisation. The staff teams in the two NGO services changed quite significantly during the period of the study, as a result of the organisational restructure, staff leaving the organisation, being moved to another service or acting up in a more senior position. Teams also included casual staff who filled ad hoc vacant positions in shifts, or replaced, in the short term, staff who had left the service. These changes meant that new staff
coming into the service on a casual or more permanent basis were unlikely to have had training in Active Support, and if they had previous training it would be unlikely to have been adapted to working with service users with neurotrauma. The semi structured interviews clearly demonstrated the impact on service users of staff changes, when there are no mechanisms to induct new staff coming into the house about practice expectations. One service user said,

There was a lot of new staff and they were not really functioning very well…a few of the staff are gone, they’ve all been replaced with new staff, or – what do they call them – ‘share nurse’. So, once they get a routine they’re okay. But at the beginning, they’re not okay. Just get a bit frustrated because the other staff know everything you do, and the new staff don’t. You’ve got to tell them, ask them or disagree with them. But I suppose it’s hard when they’re new…the thing is, with half of them, you don’t understand what they’re saying…yeah, that’s hard. [Catherine, service user, NGO 43].

Staff members were very aware of the need to orientate new staff to Active Support practice, although a little uncertain how to do this,

…we’ve got a whole new team too, and – well not a whole new team but half the team members are new, so they’re coming into an environment where there’s been a lot of changes, and they’re good changes, and hopefully they’re learning good habits. Just it’s all the little things, like the way you do things, the way you speak to people. [Faith, staff, NGO 39].

We’ve also got a lot of new staff as well that are trying to swim fast, basically. But if we can catch them at the beginning and go, this is the right way to approach this job and approach the clients you’re looking after, then we’ve won, rather than them thinking the old way and having to learn the new way. If they just learn the new way, I think it would be great. This approach came into this house while I was doing my Cert IV, so I kind of got a double whammy of this. Kind of looked at it and went, this is what I’ve been trying to do anyway”. [Heather, staff, NGO 43].

We’ve been so short-staffed, we’ve often had two people that we’ve been working with in the morning who are new. It’s been quite stressful…but I’m not wasting my time for a casual who’s coming in, going through all this when I’ve already taught the whole shift, eight hours just about, how to get through the shift. I cannot – I’m not a robot, superhuman. I just can’t extend to that”. [Suzanne, staff, NGO 43].
As these comments illustrate, changes in staff, new staff without Active Support training, and the absence of strong practice leadership meant the quality of support was inconsistent and there was weak team work. Talking about the quality of staff support, one service user’s father said,

“It depends who’s on. Because they vary a little bit, in terms of how much the staff want to be involved”. [Father of service user, NGO 39].

Staff members pointed to the difficulties of communicating among team members, following things through and knowing what other staff were doing with service users,

We need a way of communicating, whether it’s a board – the problem with things being put up on a board to be read is having the time to read them. Whether or not it’s Darren [frontline manager] sends an email out to us so we can read them in our own time, we should all get the same information on the same day. This is the important thing; otherwise you’ve got three people working here, two people – one person’s already been told that someone’s meant to be doing something, and the other two haven’t. Are we getting the right information from that person or aren’t we? We were talking about getting one of the chopper things that all they had to do was push down. I don’t know if we’ve got it yet. That was six months ago. Everything takes forever. It’s like, we’ll discuss it, yes, it’s going to happen, but by the time it turns up, no one remembers why we were getting it. [Heather, staff, NGO 39].

So, you’ll find, for example, the guy who makes his own cereal. He often has a sandwich in the morning. He has a bowl with a spoon. Often, he’s able to get that bowl and the spoon and bring it to the staff and say, ‘Could I please have some jam?’ and you will do it for him, give it to him. He would make his own sandwich, toast it and eat it. Other staff prefer to make the sandwich and leave it on the table, and sometimes, it upsets him because he feels like you’re taking away the few things that he can do for himself. [Annie, staff, NGO 43].

The problems of communication and weak team work were apparent from the very different perceptions staff members Faith and Grant had about potential engagement of several service users,

Madeline can’t assist with anything like that, absolutely nothing. There’s nothing – I’m just trying to think of Madeline assisting with anything, but I don’t think she’s actually capable. She’s not really capable of doing anything, and Elliott too, he’s got one good arm, that he can help put his napkin on for dinner, he can feed himself. He
can play games, like Uno and Connect Four and stuff like that. Madeline can at a pinch play Uno. Yeah, I’m not sure. [Faith, staff, NGO 39].

I’m cooking in the kitchen and I’m by myself, whether Elliott’s playing up or not playing up or Madeline’s just sitting in the room, I’ll go down and say, “Come on. Come and help me down the kitchen.” Madeline can do a little bit, but like cutting, you have to hold her hand…Elliott can’t do anything. But just bringing him in and talking and just saying, “Do you think I should put a little bit of salt in that? What would you put in it?” He puts chilli sauce in everything. But being part of the cooking. [Grant, staff, NGO 39].

Disruptions to the quality of support and the challenges of the continuous process of ensuring staff are equipped with the necessary practice skills were apparent to the NGO senior manager,

…the staffing group there has changed, there’s probably been a turnover of about twenty-five, thirty percent. So reasonably stable…so I think that there were definitely improvements going on. But as I said I think we’ve stalled and even gone backwards a bit with the change of the coordinator [frontline manager] that we had and the change of staff. And I think we brought a couple of staff members in who clearly didn’t understand what Active Support was. We’ve had to manage those people out and that sort of stuff has been totally necessary but also time consuming. [Ian, NGO senior manager].

Acknowledging Active Support is a Significant Paradigm Shift

The slow pace and relatively small changes to practice associated with the adoption of Active Support by these services may be related to the differences in support needs of people with neurotrauma from those of people with intellectual disability, or subtle differences in the nature of supported accommodation services that were not taken into account in this project. As has already been indicated some staff members saw supported accommodation services for people with neurotrauma as different from the other services managed by the NGO. Comments from both staff and the senior manager suggested the services were more strongly rooted in a medical model of care than those for people with intellectual disability, and thus a significant overall shift in both management and staff practice was needed to implement Active Support. The magnitude of this shift was underestimated, and the project may have provided too few resources to the organisation and staff teams. For example, one
staff member talked about the way the service she worked in had been established almost as a hotel for service users,

We mentioned this Active Support stuff coming up, and they [staff] were like, ’What the hell?’ It was just a total foreign concept. So that was quite funny. Because when the house opened…we were kind of at the residents’ beck and call really. And we did that because we wanted everyone to fit – be happy and comfortable and coming into a new environment and – So that’s the way it was. And then Active Support came up, and then we had some people who were quite happy to have all this stuff being done for them, being told, ’No, you need to get in and do it yourself, even if you find it hard. You need to give it a shot.’ ’But I know I can’t do it, so why are you making me do this? I don’t want to do it. It’s my choice. You go on about choices all the time.’ So that’s been tricky. [Suzanne, staff, NGO 43].

And because at the moment I think there’s been a tendency for this service and the other house around the corner supporting people with acquired brain injuries to be treated somewhat differently from other houses where we might support people with different needs, not high physical care needs but cognitive impairments, so people’s intellectual disabilities. I think our approach to those houses have been quite different. I think they have always been treated differently partly because they’re TAC funded, partly because they’ve got all these therapists in place, partly because the healthcare needs are really high and that’s been the focus…TAC programs have always been therapy-led programs, therapist-led programs. [Ian, NGO senior manager].

The NGO senior manager went on to identify some of the underlying tensions between a support model and one that was more focused on health and medical recovery, which had to be negotiated by staff as part of implementing Active Support,

I think the staff are very much focused on the health and medical model. Look I think there’s some frustration at times from the therapists that what they’re trying to get the staff to do isn’t being done in the way that they would like it. I don’t know if there’s exactly a conflict I just think for example I think there’s a lot of clients have very elaborate and detailed care manuals that are updated pretty often and staff are expected to keep on top of that…and then you’ve got other things such as the involvement of specialists and health specialists and the staff trying to negotiate the advice they’re getting, but also the fact that they’ve been advised to provide person
centered active support and I guess one of the issues there would be where does person centered active support fit in with all this, the health needs of the people there”. [Ian, NGO senior manager].

**Implementing Active Support in the Context of a Therapeutic Team**

Most of the service users in the study received individualised support from a range of Allied Health professionals; physiotherapists, occupational therapists and dieticians. These professionals were important members of the staff team who influenced the type of support that frontline support staff were expected to provide to individual service users. As several staff suggested their perspectives or instructions potentially compromised or placed little importance on other expectations about staff practice. For example,

> What I’ve noticed is that when we go to team meetings, discussions with the team, are often about critical updates from therapists, it’s about dealing with concerns about how we’re supporting someone with their pressure areas or a lot of those things seem to take the priority over person centered active support discussions, about how to sort of, little and often and everyone has potential and graded assistance, all that sort of stuff, it seems to be harder to get that to the top of the agenda is what I’ve experienced. [Ian, NGO senior manager].

> …we need to give the choice to the clients what they would like to eat or anything. But sometimes we have to follow the therapy guidelines. All the clients, they have different therapists involved. Speech therapists, dieticians, psychologists and everything, and sometimes to make sure that their health has been looked after properly then we cannot give them a choice. It’s not like we are making decisions, like the dietician has provided two weeks of weekly menu for the breakfast, different menus. But then some of the staff said ‘what about the client’s choice?’ Because we learned this. So, it’s a question that has come up for me. I said now I know that we should be asking the clients but then if we do that, that has some negative, not negative but has some concern too regarding their health and it has been because of that we don’t want clients getting admitted into hospital. Because sometimes we just have to follow the different therapist’s guidelines to making sure that particular client’s health and wellbeing has been reached properly. [Darren, frontline manager, NGO 43].
The comments made by the father of one of the service users captured potential synergies between therapy interventions and day to support from support staff, and the importance of team work that brought together perspectives of Allied Health professionals with the type of support paradigm represented by Active Support,

I remember there was a meeting that I attended, it was in the dining room up there, with all the Allied Health people and whoever was running the show here, and the TAC person. I did mention that, as part of the Occupational Therapy type activities, Madeline could be involved in some of the things that are happening [in the service]. She could be even just be involved in helping to fold up towels, or tea towels, or just things like that. I don’t think it happens. And I see images when Madeline goes to her cooking class, I see her stirring things – But also Madeline, she’s not a bad cook and she used to cook heaps of stuff, didn’t you Madeline? And she knows ingredients that go into different things. She could be in the kitchen and making suggestions. And I just don’t think it happens. And I reckon there’s all sorts of little things that Madeline could help with. [Father of service user, NGO 39].

As well as the limiting aspects of some professional advice that some staff saw, from a more positive perspective staff members drew attention to the benefits of having allied health professionals as part of the staff team, and their potential role to provide advice about application of some Active Support strategies to their service users. As one staff member said,

We can’t as a team go yes, we’re going to implement this now because we also have to have things like physios and OT's and stuff involved to make sure that we’re not asking someone to do something that they can’t do, and we’re not doing it in a way that’s potentially dangerous for them to be doing it. You can’t be standing beside someone holding them up while they mop the floor either…it’s that step between the conception – we all brainstorm, we all go yes, we can do this, it can fit into the schedule here, if it can be done – so we can start introducing it and getting the specialists involved to go yes, you can and this is how we should be doing it. Its three months later before anything starts”. [Heather, staff, NGO 39].

Staff recognised the importance of knowing service users well if they were going to implement Active Support but it was not clear to what extent Allied Health professionals had been consulted or involved in the introduction of Active Support. This was an oversight of the project as they were not invited to any of the training sessions.
Some staff were very tuned into the cognitive limitations of individual service users, particularly memory issues, and several emphasised the importance of knowing the person and adapting support to take account of their particular strengths and weaknesses,

If you ask Madeline, you can’t give her too many options. So, everyone’s got to know each client. And I found when I was working in different houses, I’d spend the first three months working out how the guys are, how they’d react to things, their sense of humour and what they like. [Grant, staff, NGO 39].

Yeah, well they’re individuals. You know, so they all react differently to different tasks and different ways that you approach things. Like if I approach Catherine with something it might work, but if I approached it with Kirk, it might not work exactly the same. It needs to be individualised. [Nicole, staff, NGO 43].

Data on the perspectives of staff from the interviews and some of the observational data suggest however that staff were less clear and may have been making assumptions about service users’ physical limitations. For example, staff’s interpretation of the Active Support essential ‘graded assistance to ensure success’ was very focused on completing physical tasks for service users, rather than providing hand-over-hand assistance to enable them to complete a task. Many staff gave examples of engaging service users in conversation as they themselves undertook tasks they thought a service user would not be able to do, or of carrying out a task on the instructions of a service user whom they thought could not do it for themselves. For example,

Those that can make their own breakfast will do it with a bit of assistance. Those that can’t do anything might direct you in what they want and you will do it for them. But you’re working with them. So, you’re interacting with them the whole time. [Annie, staff, NGO 43].

I bring Elliott into the kitchen, I park him in the middle of the kitchen, and he is there while I do things. And, he enjoys it as well, because they’re not being parked and left, they’re being involved in everything that’s happening. And, I chat. Everybody does chat, but if he’s in the kitchen, in the hub of it, and they like that. [Faith, staff, NGO 39].

They’re doing all the bits that they can themselves and I’m just filling in for the bits that they can’t do…the fact that – Russell would be the only one that could actually potentially stir the pot…even if all they can do is sit there and talk to you about what you’re doing and be interested in what you’re doing, then they should be talking –
sitting there and talking to you about it, if that’s what they choose to be doing”.

[Heather, staff, NGO 39]

Normally, she would put her cereal in the bowl and the milk, but she would need a bit of assistance carrying it to the table because she can only use one hand. Same for if she’s making a diet shake. She can instruct you and show you and then – she would ask you what you’re doing and put it on the table for her. So, it’s more half and half.

[Annie, staff, NGO 43]

Because Phoebe only really has one useable arm, so you do a lot of the work for her but she does like to taste test and you know, she does give you very detailed instructions. Which I think is why it might take the longest, but it’s kind of nice to have that detail as well. [Nicole, staff, NGO 43]

The practice of good Active Support with people with intellectual disability goes beyond social inclusion in the milieu and emphasises the right amount of staff contact, preparation of activities, and assistance to participate in meaningful activities ranging from prompting to hand-over-hand support. People with intellectual disability would rarely be able to give the type of detailed directions about how to complete a task that some staff described service users in these services as doing. This type of direction to complete a task such as cooking, however clearly falls within the realm of engagement in meaningful activity and is different from being involved in social chat whilst a staff member does the household tasks.

A point of difference between people with intellectual disability and those with neurotrauma may be the functional limitation due to physical or neurological trauma experienced by this group of services users, meaning that using hand-over-hand assistance to enable completion of a task could potentially be harmful or inappropriate. It seemed however that staff were making assumptions about this rather than having access to advice and guidance on this issue. This is an area where Active Support training and observational recording may have to be adapted for this service user group. It is also an area where involvement of the therapists working with an individual on their rehabilitation and independence skills appears to be an important consideration in implementing Active Support with people with neurotrauma.

Significantly however the senior manager, in his thinking about the implementation was that it was really important to get the Allied Health staff involved to support the approach being taken across the organisation,

So, I think a lot of what they’ve got in place is pretty much the same thing, but maybe it would help if we’re using Active Support everywhere else in the organisation,
maybe we need to find a way of getting the therapists to be using it too. So, we’re not doing one thing over here, Active Support, another thing over here, working with therapists, we want to try and combine it. [Ian, NGO senior manager].

Discussion and Conclusions

Problems with recruitment of organisations to participate in the study, and the turnover of direct support and front line managerial staff in these organisations, are reflective of the demanding context of disability services in a time of significant reform. The study took much longer than anticipated, and staff changes interrupted the smooth implementation of a new practice in the three group homes involved. Nevertheless, valuable insights have been gained into the quality of support for people with neurotrauma living in supported accommodation services, the applicability of Active Support to this population and factors affecting implementation. The data suggests that staff, residents and the family member involved in the study supported the introduction of Active Support but that its implementation is not easy and requires consideration of additional issues to those already in the literature associated with services for people with intellectual disabilities.

Overall these data are indicative of a poor quality of day to day support for people with neurotrauma living in group homes. This should be a concern to the TAC as the funder of supported accommodation services for clients such as those who participated in the study. Services tended to reflect a medical rather than social model of care, and direct support staff more concerned with doing things for people rather than enabling service users to be engaged in meaningful activities and social relationships whilst in their homes. In these services considerable reliance is placed on visiting therapeutic input provided by Allied Health professionals or outings to activities in the community. Opportunities for engagement in the home in regular household activities do not appear to be part of everyday practice or expectations of managements. Front line managers do not play the role of a practice leader for staff, and appeared more concerned with organisational paperwork and procedural compliance. Of concern too was the apparent absence of collegial team work between house staff and Allied Health professionals, where the latter are perceived as directing rather than collaborating with house staff.

There was strong support for the adoption of Active Support and indications from both quantitative and qualitative data that practice that reflects this approach was beneficial for service users and can lead to greater levels of engagement. As previous research in intellectual disability services shows (Mansell & Beadle-Brown, 2012) and the data in this
study has demonstrated however, implementing Active Support is challenging. To practice
Active Support evidence suggests that staff should have class room based and hands on
coaching in Active Support (Mansell & Beadle Brown, 2012). This means that once initial
training in Active Support has been completed, this type of training should be a mandatory
part of induction for new staff to avoid staff turnover reducing the proportion of trained staff.
To reach good levels of quality and consistency, Active Support practice must be reinforced
and modelled by front line managers who, therefore must act as practice leaders, with the
skills to coach staff, and lead team work focused on Active Support, as well as individual
supervision of support staff. In addition, organisational messaging from senior staff and
public facing communications needs to echo expectations that this type of practice has been
adopted by the organisation and is expected from all staff. As our data demonstrates, in this
study implementation of Active Support was disrupted by staff turnover exacerbated by
organisational restructuring which meant that part way through the study a proportion of
staff and managers had not been part of the original cohort that had been trained and there
was no strong managerial driving force for its implementation.

The study has also highlighted previously unexplored issues about implementing
Active Support in services for people with neurotrauma. It suggests new support practice
approaches, such as Active Support, must involve Allied Health professionals or other
therapists, rather than just staff from the supported accommodation service. It was clear that
Allied Health professionals play a key role as part the team in these services and in
supporting each individual client. Their role as part of each client’s support network and
influence on direct support staff suggest they need to both understand and encourage the
implementation of Active Support practice by all staff. The findings suggest too, that Allied
Health professionals have an important role to play in helping support staff articulate and test
their assumptions about each individual’s physical limitations and the appropriateness of
strategies such as hand over hand assistance. The reluctance of staff to use this type of
assistance for fear of harm to an individual also reinforces the person centred nature of
Active Support and the importance of knowing well the person being supported from many
different perspectives. The findings suggest too the need to work more closely with families
and service users themselves when a new model of support such as Active Support is
introduced into a service.

One of our observations from the experience of training staff from the organisations
involved in the study is the need to adapt aspects of the training materials to more clearly
reflect the possibilities of Active Support practice with people with neurotrauma. For example, development of video clips that portray people with neurotrauma rather than intellectual disability and that illustrate some of the differences in approach that may be required, such as including Allied Health staff as part of the team and consulting with them and others about an individual’s physical limitations. Training materials more tailored to people with neurotrauma must also recognise competing priorities between support for engagement and physical health care issues, as well the extent of paradigm shift that will be necessary if Active Support is to adopted in services that have traditionally been seen as therapy led, and different from those that support people with intellectual disability.

The study has provided evidence about the viability of implementing Active Support as a preferred practice for front line staff in supported accommodation services for people with neurotrauma, and identified the need to devise and support robust implementation plans if practice is to be embedded in services. These must, at a minimum involve;

- adaptation training materials to illustrate possibilities of Active Support for people with neurotrauma;
- leadership by senior and front line managers to reinforce and reward changed practice;
- class room training and hands on mentoring for all direct support and front line managers;
- strengthening of practice leadership (coaching, modelling, team work, supervision and focus on direct practice) by front line managers;
- involvement of the Allied Health professionals who form part of the support team for each individual in the service.

It will be important that research continue to be conducted on the implementation and outcomes of Active Support for people with neurotrauma. This will ensure that further evidence is available to demonstrate the quality of life benefits of service users in order to inform commissioning and funding of services, as well as guide organisations on ways to embed good Active Support practice in their day to day work.
References


Every Moment has Potential – an introduction to Active Support on line training resource. http://www.activesupportresource.net.au/


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