



# Executive Summary of the ‘Wait-times’ Project 2012

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### List of Acronyms

AT	Assistive technology
AEAA	Aids and Equipment Action Alliance
MND	Motor Neurone Disease
SWEP	Statewide Equipment Program
VAEP	Victoria’s Aids and Equipment Program (run by Ballarat Health as SWEP)

The priority is to ensure access to appropriate, timely, affordable, and high-quality rehabilitation interventions, consistent with the CRPD, for all those who need them.<sup>1</sup>

–World Report on Disability 2011:121

## Aim of the ‘Wait-Times’ Project

The State Trustees funded the Aids and Equipment Action Alliance (AEAA) to conduct the ‘Wait-Times’ Project. The purpose of the project is to investigate wait times for assistive technology (AT) in Victoria and to present policy options. The project is based on concerns with the wait times faced by Victorians eligible for equipment funding through the Victorian Aids and Equipment Program (VAEP), which operates as the Statewide Equipment Program (SWEP).

## Approach of Project

This project reviewed relevant literature and policy. Perspectives from a range of stakeholders were canvassed through an emailed data-gathering tool and by targeted interviews. Stakeholders included assistive technology (AT) scheme funders, AT consumers and AT practitioners. The information gathered was evaluated in light of the literature and from that policy recommendations were drawn up.

## Summary of Key Recommendations

Three recommendations were made on the basis of the literature and of the data collected by the Wait-Times Project:

- 1. An entitlement approach.** That is, provide approved equipment at time of need, similar to the Pharmaceutical Benefits Scheme. Increased resources are required to implement this recommendation.
- 2. ‘Purchase and reimburse’ model.** That is, improve SWEP’s flexibility by reimbursing the subsidy amount. This recommendation has organisational and short-term resource implications.

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<sup>1</sup>WHO (2011) *World Report on Disability*. Malta, WHO.

**3. ‘Concurrent wait-list’ or ‘approved in principle’ model.** Consumer enters the ‘wait period’ at the point of indicative need: in other words, the point when a need is identified even if not fully assessed. Therefore, the time-consuming processes of full assessment, equipment trial and report writing occur concurrently with the SWEP wait period.<sup>2</sup>

This Executive Summary outlines the Project’s background and summarises a range of literature and new data related to issues around SWEP wait times. Arguments in support of the three recommendations are presented on pages 11-14. The Executive Summary is underpinned by additional documents (Annotated Literature Review and Appendices).

## Background

The limitations of equipment (AT) funding schemes have been documented in Australia<sup>3 4 5</sup> and in Victoria.<sup>6 7 8</sup>

The state government scheme that currently provides for Victorians is the Victoria’s Aids and Equipment Program (VAEP), administered by Ballarat Health Services and operating as the Statewide Equipment Program (SWEP).<sup>9</sup>

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<sup>2</sup> SWEP advise ‘approval in principle’ is the current process with vehicle modifications

<sup>3</sup> National People with Disabilities and Carers Council (2009) *Shut Out: the experience of people with disabilities and their families in Australia - National Disability Strategy Consultation Report*. Canberra, Commonwealth Government.

<sup>4</sup> AIHW (2006) *Therapy and equipment needs of people with cerebral palsy and like disabilities in Australia*. Canberra, Australian Institute of Health and Welfare.

<sup>5</sup> Barbara, A. & Curtin, M. (2008) *Gatekeepers or advocates? Occupational therapists and equipment funding schemes*. Australian Occupational Therapy Journal, Vol 55, 57-60.

<sup>6</sup> Pate, A. & Horn, M. (2006) *Aids and equipment for Victorians with disabilities - entitlement or hand-out? A Position Paper - Recommendations for an effective Victorian Aids & Equipment Program for the 21st Century*. Research and Social Policy Unit, Melbourne Citymission.

<sup>7</sup> Wilson, E., Wong, J. & Goodridge, J. (2006) *Too little too late: Wait times and cost burden for people with a disability in seeking equipment funding in Victoria*. Melbourne, Scope (Vic).

<sup>8</sup> NB VAEP also covers Electronic Communication Devices and this scheme is run by Yooralla ECDS. This section of AT was not the focus of the Review.

In 2010, the Equipping Inclusion Studies<sup>10</sup> demonstrated that for many Victorian consumers, the partial funding subsidy that VAEP provided did not deliver hoped-for outcomes. The majority of VAEP Scheme users require multiple AT devices, yet no safety net exists to support the need to find multiple top-up funds. Economic evaluation identified that,

...elements of AT cost are carried by funders (including AT users) other than the Victorian Aids and Equipment Program; and...key elements of AT were not covered at all. This results in those in need being at risk of going without needed AT and the outcomes it enables. On criteria of both efficiency and equity, this finding has policy implications for the extent of subsidy support deemed appropriate for this low income and special needs group. (Layton et al, 2010:13)

## Current Context

Since 2010, Victoria's AT scheme (SWEP) has undergone an extensive technical restructure. This includes a decrease in the number of issuing centres, increased transparency of allocation systems and a state-wide co-ordination of reissue, repair and maintenance. However the ongoing presence of wait lists (up to 9 months) indicates that SWEP funding is insufficient to meet current demand.<sup>11</sup> In the absence of sufficient budget to meet demand, demand will outstrip supply. When this occurs, schemes such as SWEP are forced to prioritise eligible consumers and therefore to ration services. It is in this context that State Trustees funded AEAA to conduct the 'Wait Times' Project.

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<sup>9</sup> KPMG (2006) *Final Report of the Review of the Aids and Equipment Program*. Victorian Government.

<sup>10</sup> Layton, N., Wilson, E., Colgan, S., Moodie, M. & Carter, R. (2010) *The Equipping Inclusion Studies: Assistive Technology Use and Outcomes in Victoria*. Melbourne, Deakin University

<sup>11</sup> It is noted that there is no wait list for oxygen, or for SAEAS clients (Supported Accommodation Equipment Assistance Scheme) however all other AT are subject to wait times.

Since State Trustees provided these funds in late 2011, several initiatives have occurred within SWEP and the AT sector:

1. Priority of Access Guidelines (published 2<sup>nd</sup> February 2012)<sup>12</sup>
2. Top-Up Fund for Children established by the Victorian Government (May 2012)<sup>13</sup>
3. A current wait-list audit<sup>14</sup>

The '**Priority of Access**' system is intended to 'ensure those who need the equipment urgently are readily identified, while subsidy for equipment continues to be provided to all those who are eligible in an equitable manner'<sup>10</sup>(p 2). Urgency is determined through rating safety, in/dependence and health maintenance on a minor–major–severe scale, against the possible, likely or imminent likelihood of adverse events occurring. Issues that are both imminent and severe on these matrices are deemed urgent and bypass the waiting list. From a health economics perspective, it could be said that SWEP, through these actions, is replacing 'rationing by queuing' with 'rationing by prioritization',<sup>15</sup> in its endeavours to balance demand that outstrips the budgetary capacity for supply.

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<sup>12</sup> 'Risk to clients based on potential consequences or 'implications of non-provision' are assessed in a context of relative likelihood, providing a structured way to communicate urgency of need and articulate a reasoned approach to priority of access" Page 1 from <http://swep.bhs.org.au/sites/default/files/forms/SWEP%20Priority%20of%20Access%20Guidelines%202%20February%202012.pdf>

<sup>13</sup> 'The Top-up Fund for Children provides families and children with funding to meet the difference between existing subsidies and the full cost of eligible mobility equipment.'

<sup>14</sup> 'SWEP is continuing to conduct an on-going wait-list audit, with current statistics indicating that 16% to 33% of applications are cancelled prior to order. Some of this is due to the length of time clients have been waiting for equipment, and we are hopeful that will reduce with some of the initiatives put in place.' SWEP Prescriber Newsletter 4 July 2012: p4

<sup>15</sup> Kreindler, S. A. (2010) Policy strategies to reduce waits for elective care: a synthesis of international evidence. *British Medical Bulletin*. 95:7-32. Epub 2010 May 10.

While the ‘most urgent’ need is met, the question remains whether the social contract is being fully met when a ‘major’ but not ‘severe’ need remains subject to wait times. (See<sup>16 17</sup> for a discussion of the social contract and adequate support)

A Critical Path Survey was conducted on current practice and on delays in AT provision,<sup>18</sup> through AEAA member organizations and OT Australia Victoria ‘Working with Adults Living with Disability’ Special Interest Group. Data was obtained from 5 AEAA members and/or organizations as well as from the AT funding schemes—Department of Veterans Affairs (DVA), Motor Neurone Disease (MND) Association, Calvary Progressive Neurological Service and ENABLE New Zealand. Key findings from the literature review and from the critical path survey are summarised here.

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<sup>16</sup> Goggin, G. & Newell, C. (Eds.) (2005) *Disability in Australia: exposing a social apartheid*, Sydney, University of NSW Press.

<sup>17</sup> National People with Disabilities and Carers Council (2009) *Shut Out: the experience of people with disabilities and their families in Australia - National Disability Strategy Consultation Report*. Canberra, Commonwealth Government.

<sup>18</sup> AT Critical Pathway data collection August–October 2012

## Key Findings

### Best Practice

1. The literature identifies seven 'best practice' steps in AT provision.<sup>19</sup> These steps represent a 'critical path' of service delivery:
  - i. Problem identification;
  - ii. AT assessment with an AT practitioner;
  - iii. AT trial (across multiple environments of use, adaptation, training);
  - iv. AT prescription/recommendation made & application for AT funding;
  - v. Provision (includes fitting, custom-setup, sign-off);
  - vi. Review (clinical review and AT performance review);
  - vii. AT re-evaluation (needs assessment of consumer, of equipment lifecycle).

(NB The critical path data collected for this project found that there is virtually no opportunity for Steps 6 and 7 to be enacted in current provision models.)

### Literature Review

2. Published literature mainly addresses wait times for health services including rehabilitation and surgery. A small amount of literature addresses wait times for aids and equipment (otherwise known as assistive technology or AT). Wait-lists for AT services are found to have detrimental impacts upon health status including well-being, physical condition and psychological status. A number of studies identified stress, dissatisfaction, poorer participation outcomes, and higher AT abandonment are linked with length of wait (for more information, see Literature Reviews at [www.aeaa.org.au](http://www.aeaa.org.au)) . One study mentions the beneficial impacts of waiting such as preparation and adjustment. Aversion to waiting is a key theme. Another study found that motivated parents of children awaiting services manoeuvre within the system to move up the wait list.

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<sup>19</sup> ARATA (2012) *Assistive Technology within the NDIS*. Coloundra, ARATA.

also see Steel, E., Gelderblom, G. & De Witte, L. (2011) *Development of an AT selection tool using the ICF model*. *Technology and Disability* 23 (1), 1-6.

Information and transparency around realistic waiting periods and prioritisation decisions were found to assist consumers in coping with wait-times. To wait in excess of 5 weeks for a service was identified as problematic yet waits as long as 2 years were reported for surgery or rehabilitation.

Ideally, provision schemes run on an entitlement approach. In other words, if a consumer is eligible for a service and is assessed as requiring the service, the service is delivered. For example, consumers with a prescription for the Pharmaceutical Benefits Scheme do not wait for sufficient budgetary allocation to become available to fill the prescription.

### Data regarding Wait-times for AT

3. The Critical Path Survey collected evidence from a range of rationing strategies that occurred in the context of SWEP. This evidence has been linked to the current economic theory that identifies rationing strategies when supply is insufficient to meet demand. The strategies are described below:

a. To target supply to a manageable population, schemes attempt to limit demand by narrowing eligibility criteria or by increasing hurdles to access. Schemes thereby identify some eligible but less 'needy' applicants as 'excess demand'. In effect, the Priority of Access criteria operated by SWEP is limiting demand.

b. Prescribers cease to refer to overburdened schemes, and/or consumers do not attempt to apply or to remove themselves from wait lists. This creates 'invisible' or 'residual' wait lists which hides unmet need. Benchmarking unmet need against current waiting lists is likely to be a severe underestimation, as some Victorians with disabilities report their decisions to relinquish participation or to seek alternatives due to wait list 'hurdles'.<sup>8</sup>

c. Prescribers and consumers seek alternatives. These may include:

- rationing of participation (relinquish those activities for which AT is needed);
- relying on personal support;
- relying on private purchase by families;
- utilising superannuation or income protection insurance;
- seeking philanthropic support.

Department of Human Services fund an Equipment Library for short-term trial and loan, managed by the Independent Living Centre. Small schemes such as the SCOPE Equipment Fund have developed to 'top-up' or to supplant the perceived limits of Victoria's AT scheme (SWEP). Several of these are directly government funded, for example the MND Association's Equipment Library and the Top-Up Fund for Children.<sup>10</sup> Other schemes are assembled from a variety of sources, for instance the equipment store held by Calvary Health for progressive neurological clients. At times AT is sourced from services that were not designed nor intended for provision of AT, such as HACC (home and community care) funds and ISP (individual support packages).

Multiple pathways, queues or systems are noted to be a technically inefficient way of providing a service.<sup>20</sup> Extensive local knowledge by prescribers, consumers, and families is required to locate and to obtain these alternatives and to understand the complexity of application processes and the arrangements for servicing/maintenance. This array of disparate schemes leads to two key problems.

First, an 'opportunity cost' occurs when money, intended for other purposes, is spent 'topping up' or fully purchasing AT. In other words, the benefits that could be gained from the alternative use of these resources represent an opportunity cost.

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<sup>20</sup> Kreindler, S. A. (2008) Watching Your Wait: Evidence-Informed Strategies for Reducing Health Care Wait Times. *Quality Management in Health Care*, 17, 128-135.

Examples include consumers relinquishing the personal support hours needed for showers or community access, to pay the gap costs for needed AT.

Second, using alternate funds in this way serves to mask unmet need. That is, the 'participation poverty'<sup>21</sup> and opportunity costs experienced by consumers and services in allocating money to address funding shortfalls, may not be taken into account.

d. If unmet need is not identified, the real supply shortfall will not be calculated and patterns of undersupply and under-resourcing will continue unaddressed. Recent literature, which identifies substantial 'unknown, unmet need'<sup>22</sup> particularly for older people, supports the premise that unmet need is likely to be significantly higher in Victoria than indicated by the SWEP waiting list.

Note on other schemes: DVA Rehabilitation Appliances Program operates without a wait list and generally issues AT within 24 hours of approval, however the Program reports that the most common source of delays is access to AT practitioners for assessment, documentation of prescription and for follow-up. Enable New Zealand reports similar experiences, suggesting a continuous quality process is required to examine and to address system 'traffic jams'.<sup>15</sup> SWEP notes the availability of AT practitioners is a substantial 'critical path' issue. For example, there are waiting periods of up to 5 months to obtain assessment from an AT practitioner and difficulty to locate suitably experienced practitioners for follow-up if original prescribers leave.

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<sup>21</sup> Senate Community Affairs Reference Committee (2004) *A hand up not a hand out: Renewing the fight against poverty—Report on poverty and financial hardship*. Commonwealth of Australia.

<sup>22</sup> Gramstad, A., Storli, S. L. & Hamran, T. (2012) "Do I need it? Do I really need it?" Elderly people's experiences of unmet assistive technology device needs. *Disability and Rehabilitation: Assistive Technology*, Posted online on July 17, 2012. (doi:10.3109/17483107.2012.699993).

'Our clients have no time to wait. They can barely wait for us to arrange AT from the loan pool.'

–OT prescriber describing the provision process for progressive neurological clients

## Recommendations

Society has obligations to meet the needs of its citizens. Victorians living with disability—the impact of which can be mediated by AT—can expect governments to address their needs through AT funding schemes, such as SWEP. From an economic perspective, efficient schemes feature 'allocative efficiency' (that is, providing services because it is the right thing to do) as well as 'technical efficiency' (that is, the best way to do it). The challenge from a policy perspective is to realise the potential of AT schemes by ensuring adequate supply (arguing for a sufficient portion of governments' resources) and by delivering AT in an effective manner.

Technical efficiency benefits can be seen in VAEP's devolution from a multiple issuing centre model to the current state-wide service offered by SWEP. However, little progress has been made from an allocative efficiency perspective, as evidenced by the rationing mechanisms still in place and by the alternative pathways which are sought to bypass scheme delays.<sup>13</sup> The presence of additional focal and time-limited schemes (from within government and outside government) to address the shortfalls of existing government schemes, is highly inefficient from health economic and policy perspectives.<sup>23</sup>

From a human rights perspective, The World Report on Disability (2011) calls on stakeholders to 'assess existing policies, systems, services, and regulatory mechanisms, identifying gaps and priorities to improve provision' <sup>1</sup> (p122). In light of this statement, the AEAA offer the following recommendations:

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<sup>23</sup> Australian Public Service (2009) The Australian Public Service Social Inclusion Policy Design and Delivery Toolkit

#### a) An entitlement approach

The Aids and Equipment Action Alliance (AEAA) holds the position that AT is a critical enabler for many Victorians and that they have a right to AT. Therefore the primary recommendation is an entitlement approach, where AT is provided based on documented need. Eligibility for SWEP is clearly delineated and the prescriber assessment and application process, complemented by the recently developed SWEP Clinical Review Panel, is accepted as an indicator of legitimacy. Current budgetary constraints mean otherwise eligible applications are filtered through a priority access system. This limits legitimate consumers from meeting their participation goals.

To implement the entitlement approach is an 'allocative efficiency' measure. Societal resources are allocated to those who require them. This requires increased budget and governmental action to fund SWEP accordingly. Steps b) and c) described below are 'technical efficiency' measures, and as such represent two immediate steps that could be implemented without placing extra burden on the public purse.

#### b) 'Purchase and reimburse' model

SWEP does not reimburse any AT purchased privately.<sup>24</sup> This approach has been shown to cause significant hardship when AT is required and applications are approved, yet AT resources are not available. The unmet need that occurs during the wait for budgetary availability represents a risk in terms of rights, outcomes, and downstream costs. Other schemes such as Workplace Modifications Scheme allow consumers to purchase agreed AT, and then be reimbursed agreed costs.

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<sup>24</sup> 'It is important to note that SWEP **does not** reimburse you for the cost of aids, equipment or modifications either before or after you have applied for assistance from the program.' Downloaded from <http://swep.bhs.org.au/node/126>

A proportion of SWEP applicants note that while they are not in a position to fund AT outright, they would be able to locate temporary funds if reimbursement is possible within a 9 month period.

Professor Rob Carter, Foundation Director of Deakin Institute for Health Research and Chair of Health Economics, Deakin University advises that a purchase and reimburse model is an economically valid proposition, if the payment cap is set at time of purchase. Two potential problems arise with such a model. First, schemes may find themselves responsible for greater outlays if AT costs rise during the wait period for reimbursement. Given that SWEP currently contributes a set subsidy rate, it is not envisaged that this would be a barrier. Second, an equity issue may arise between those who are able to borrow during the 'gap' period and those who cannot. It is proposed that the philanthropic sector and local equipment schemes (for example SCOPE Equipment Fund), adjust their support so that low cost loans are available for the wait period. This would represent a positive investment as consumers can avoid waiting for needed AT and money can become available after the wait period to support further consumers. This opinion represents an external perspective upon the SWEP scheme, assuming that the wait of up to 9 months is basically a liquidity issue. If this is the case, there appears to be no economic reason why accepted applications must be held pending availability of funds. From a consumer perspective, this approach will speed outcomes, and will be of psychosocial benefit to recipients. From an administrative perspective, resources would be needed to lessen the impact for SWEP at point of implementation.

c) Concurrent wait-list or 'approved in principle' model

A feasible policy alternative is for SWEP to commence the 'wait' period at the point where needs are identified ('indicative need').

Similar to the indicative quotes used by builders prior to availability of funds, an indicative application by consumer and AT practitioner at the assessment/trial of the AT critical pathway (see 5: ii) will enable the wait for

SWEP funds to run concurrently with the full assessment process.

NB. Option c) addresses the most substantial critical path delay for SWEP consumers, namely the time lag from approval to issue. As mentioned, delays can occur at various steps of the critical path outlined in Appendix 2. It is advisable to take an ongoing quality approach to wait times within the AT assessment, trial, prescription, and provision critical path to ensure its maximal efficiency.

## Further Options

Interviewees in the Project raised a range of possibilities for improving AT provision<sup>13</sup>. These have been mapped against Kreindler's 2010 review of supply and demand strategies to manage waiting times<sup>12</sup> and are described in the Annotated Bibliography. Many of these require actions are beyond the scope of SWEP or DHS, nonetheless, the data has been captured and is presented below:

1. To approach the private health insurance industry body<sup>25</sup> to address the absence of AT insurance. Potentially, this could be marketed as 'future-proofing' insurance.
2. The impacts and outcomes of AT provision must be linked with government-ratified outcome areas. While broad outcomes are being offered in current high-level policy documents,<sup>26</sup> local programs do not map the benefits of AT provision to these outcomes. This limits the perceived benefit of AT provision.<sup>27</sup>

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<sup>25</sup> Orthotics and wigs have some limited availability through private health schemes

<sup>26</sup> Commonwealth of Australia (2011) National Disability Strategy 2010-2020

<sup>27</sup> Layton, N. & Wilson, E. (2010) Doing disability policy better: learning from research and policy change activities for The Equipping Inclusion Studies. IN BIGBY, C. & FYFFE, C. (Eds.) *State Disability Policy for the Next Ten Years - What Should it Look Like? - Proceedings of the Fifth Annual Roundtable on Intellectual Disability Policy*. Bundoora, La Trobe University

It is recommended that AT provision and AT program effectiveness is evaluated through the development of outcome tools based upon the UN Convention on the Rights of Persons with Disabilities<sup>28</sup> and the WHO ICF.<sup>29</sup> This will extend the evidence base for the effectiveness of AT. This is likely to indicate the need for increased budgetary resources to address Priority of Access needs more fully—that is, to cater for individuals with documented needs on the Priority of Access matrices but who fall below the current urgency versus budget calculation.

3. Act to streamline the supply chain will have an effect on the range and on the cost of AT and therefore indirectly on the capacity of SWEP to purchase. Examples include control on design such as the common wheelchair chassis. The bulk procurement option (for example MND Association purchasing a limited range of fully optioned wheelchairs) is likely to generate cost savings but will also limit choice. In South Australia and New Zealand, prescribers give a specification but not a brand and this widens scope for reissue.
4. To increase the universal and inclusive design credentials of environments will have an impact upon AT requirements.<sup>30</sup> For example, the requirements for heavy-duty batteries, kerb climbers and a range of other mobility equipment features may change given accessible precincts and the paths of travel. This will require co-ordinated action by multiple stakeholders across a variety of environments.
5. Direct provision of tokens towards purchase cost or towards discretionary amounts to spend on low cost repairs and accessories (such as

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<sup>28</sup> United Nations (2006) Convention on the rights of persons with disabilities and optional protocol. Geneva, United Nations

<sup>29</sup> WHO (2001) International Classification of Functioning, Disability and Health (ICF), Geneva, WHO.

<sup>30</sup> Layton, N. (2012) Barriers and Facilitators to Community Mobility for Assistive Technology Users. *Rehabilitation Research and Practice*.

replacement pumps and seat covers) may contribute to streamlining the system.

To do so turns consumers into 'customers', with the potential to increase autonomy or to create increased need for support, depending upon the individual. In the case of the UK retail model,<sup>31 32</sup> consumers are able to top up tokens directly with suppliers to customise or accessorise the AT purchase. This option limits bulk purchasing power but increases personal choice.

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<sup>31</sup> Department of Health (2008) Evaluating the Transforming Community Equipment Pilots.

<sup>32</sup> Frost, P. (2007) Transforming community equipment services. *Occupational Therapy News*.