Submission to the Review of the NDIS Act 2013

Young People in Nursing Homes National Alliance

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Introduction

The Young People In Nursing Homes National Alliance is pleased to provide a submission to the review of the National Disability Insurance Scheme Act 2013. We believe that the review is timely, given that the original legislation was designed primarily for the launch of the scheme and, based on the experience of the scheme in the trial sites, it was always likely that the Act's provisions would change over time..

In this initial stage of rollout, our experience has revealed some areas where revision of the intentions and imperatives of the NDIS Act could assist the scheme to successfully achieve full rollout over the next 5 years.

This review and subsequent legislative amendment is an opportunity for the NDIS to 'grow up' and create an identity and operational capacity that is separate to government, and behave as the national social insurance scheme it was designed to be. Governments have appropriately been closely involved in the rollout of the scheme. But this jurisdictional involvement now needs to tail off as full scheme approaches in 2019/20. The set of amendments that flow from this review must mark a transition to the scheme's full independence by 2020.

In this regard, we expect that the Act will be amended further before the scheme reaches full national rollout in 2019/20, and that other Commonwealth and State/Territory legislation will change to accommodate the final design of the NDIS.

With regard to refinement and alignment of legislation across the country, two key priorities in in the lead up to full NDIS rollout are the incorporation of the *National injury Insurance Scheme* (NIIS) into the NDIS Act, and also revisions to the *Living Longer Living Better* aged care legislation.

The Alliance believes the NDIS Act could benefit from review and considered change in the following areas:

- *Alignment of the NDIS Act with the Living Longer Living Better legislation*
- *The National Injury Insurance Scheme*
- *The creation of a Chapter in the NDIS Act to establish a scheme policy function that includes cross-portfolio policy and service development*
- *Removal of the early intervention eligibility gateway to the scheme*
- *Expanding the advisory and engagement structures of the scheme*
- *Improving the planning function and processes*
- *Developing and defining a collaborative relationship with the non-service providing community services sector*

These changes are more fully described in the following sections.

1. Alignment of provisions of the Living Longer Living Better legislation to NDIS legislation and policy

The NDIS Act Review needs to examine and make recommendations on the Living Longer Living Better legislation to ensure that the legislative and policy framework of co-payments, bonds and standards does not unfairly disadvantage younger people with disability who have no other option than to live in residential aged care.

Although 4-5% of registered aged care beds are occupied by residents under 65 years, there is no guidance in the legislation about this group. With the NDIS poised to become a significant future stakeholder in the aged care system in the areas of funding, planning and workforce development, it is timely to alert government to the need to make specific mention of the NDIS and the treatment of people under 65 in the aged care legislation.

In addition to the regime of co-payments in aged care's community care area, the case of bonds and co-contributions in residential aged care is a key concern. The regime in the aged care system does not currently allow for the particular social and economic circumstances of younger people entering residential aged care and requires the same assets formula to be applied. The Alliance is aware of a number of cases where this has been done to the severe detriment of the young people concerned, including in one case where a substantial component of their assets that could have been used to self fund rehabilitation supports; and in other cases, where similar assets could have been used to participate in community life while in residential aged care.

The Alliance recommends that this Review of the NDIS Act examine the merits of amending the *Living Longer Living Better* Act to provide for exemptions to bonds in residential care and other co-payments for people under 65 in the aged care system. Such co-payments are not required in the current State/Territory disability systems. Nor are they required in the NDIS where registered providers are precluded from charging a moiety above the scheduled NDIS price list.

If aged care providers become registered providers for the NDIS, there will be a mismatch of regulations about the pricing and co-payment expectations for services provided under both regimes in regard to people under 65.

Aged care bonds have been developed on the premise that older people have had a lifetime to accumulate assets that could and should be used to support their needs in later life. Because of their relative youth, younger people have not had such the opportunity to acquire such assets. However, it is conceivable that, via external merits review, the NDIS may be forced to meet the cost of a bond for a young person entering aged care as the reasonable and necessary cost of receiving residential support. Yet there is no comparable impost on people going into residential disability services and such a levy is absent for scheme participants through the NDIS.

The 2003 McRitchie decision in Victoria that outlined the TAC's liability in regard to supported accommodation living costs, provides an example of the risk to the NDIS that might be imposed by third parties in regard to costs.

Daily Living Costs McRitchie

Leanne McRitchie had profound head injuries and extensive paralysis from a transport accident. She had spent a long period at a private rehabilitation hospital and could not be cared for at home. A nursing home was not attractive for the 20 year old girl and a "community house" was selected. The TAC refused to pay all the costs of the accommodation and required $25 per day from the Applicant towards the costs of accommodation, meals and utilities.

The TAC did not consider itself liable for ordinary living costs not specifically related to her injuries.

An appeal was lodged with VCAT and it was found that the living expenses were totally integrated into her care and therefore should be paid by TAC. It was noted that Leanne required specifically prepared food and the help of an attendant carer to eat. The decision eventually went to the Victorian Court of Appeal and was confirmed.

The TAC estimated that paying for all costs of the most seriously injured would result in a large financial impact upon its Scheme.

The new legislation now amends both Acts to disaggregate ordinary daily living costs from other support expenses which are payable as compensation under both Schemes. This change is included in an amendment to Section 60 of the Transport Accident Act and Section 5 of the Accident Compensation Act under the definition of medical service and Section 99 of the Act.

An important additional amendment is the creation of a new 18-month transition period from the date the injured person is first discharged from hospital. During this period, all accommodation and hospital costs will be paid under each of the Schemes.

There is also an 18 month period for those currently in special accommodation during which all their costs will be paid. This 18 month period is to provide time for arrangements to be made for either those leaving hospital or those who have to face the prospect of paying accommodation charges to find the appropriate accommodation.[1]

The key difference between the McRitchie case outcome and the potential for the NDIS to be liable for accommodation bonds in aged care is that, in the case of the NDIS, one government program (the NDIS) is being called on to fund the requirements of another (the aged care system), rather than the costs of care for an individual as defined by the Victorian Civil and Administrative Tribunal (VCAT). If the NDIS were to be liable for accommodation bonds as a reasonable and necessary cost, it would be funding something that would not progress the objectives of the NDIS Act (2013) for participants, the community or the scheme itself.

[1] Michael Lombard (Holding Redlich), *Workcover & TAC Amendments in Focus (Victoria)*, Television Education Network, February 2004. Available at http://www.tved.net.au/index.cfm?SimpleDisplay=PaperDisplay.cfm&PaperDisplay=http://www.tved.net.au/PublicPapers/February_2004,_Sound_Education_in_Law,_Workcover___TAC_Amendments_ Accessed 18 October 2015.

Quite apart from the risk to the NDIS in financial terms, the requirement for a younger person to pay an accommodation bond is simply inequitable and inconsistent with the NDIS – particularly since all people under 65 are likely to be NDIS participants in any case.

At the time of writing, the Alliance is aware of four instances in 2015 where NDIS participants have entered residential aged care in the Barwon and Hunter trial sites. Being an NDIS participant is clearly not enough to prevent young people going into nursing homes and the NDIS Act needs to better reflect the interfaces and collaborative activities that must occur between these two disparate areas of the human services system.

2. National Injury Insurance Scheme (NIIS)

The Alliance wants to highlight the importance of the NIIS to the NDIS in terms of the NIIS' capacity to co-develop the scheme's reform architecture in the areas of financing, service development, workforce development and equity. In its 2011 Inquiry Report, *Disability Care and Support*, the Productivity Commission recommended that the NIIS be established prior to the NDIS. However, this sequence has been reversed in practice. As a result, responsibility for the NIIS has been delinked from the NDIS and sits within the Treasury portfolio in all jurisdictions. Consequently, there is little coherence between the two schemes at a policy or legislative level, something that, for the benefit of both national schemes, must be corrected going forward.

The NDIS Act needs to incorporate the NIIS at a number of levels. To ensure the coherent and timely development of the NIIS relative to the NDIS rollout, there needs to be both governance oversight and practical involvement of the NDIA in the establishment of the NIIS. Relevant co-development of cross sector interfaces, workforce and financing must also be incoprorated into the legislation and actives of each scheme. The following sections of the NDIS Act thus need to be amended as follows:

Section 74. An additional requirement that requires the Board to report on the progress of the National Injury Insurance Scheme must be added to part 2. Our suggested wording in red and bold at 2)c.

74 Quarterly report to the Ministerial Council

1) The Board members must:
   a. prepare a report on the operations of the Agency for each period of 3 months starting on 1 July, 1 October, 1 January or 1 April; and
   b. give the report to the Ministerial Council within 1 month after the end of the period to which the report relates.
2) The report must include information (including statistics) that relates to either or both of the following in the period to which the report relates:
   a. participants in each host jurisdiction;
   b. funding or provision of supports by the Agency in relation to each host jurisdiction

c. *progress of work on the National Injury Insurance Scheme, costs related to the NDIS, recoveries from States and Territories and impacts on the NDIS scheme.*

Section 180B (1) amend to add a point (iv) about the NIIS (suggested wording in red and bold.)

1) The scheme actuary must do all of the following each time an annual report on the Agency under section 9 of the CAC Act is being prepared:
   a. assess:
      i. the financial sustainability of the National Disability Insurance Scheme; and
      ii. risks to that sustainability; and
      iii. any trends in provision of supports to people with disability otherwise than through the National Disability Insurance Scheme (for example, trends in the provision of informal supports and supports provided through support services generally available to any person in the community);
      iv. *the progress, financial modeling and sustainability of the National Injury Insurance Scheme.*

3. Establish a Policy division in the NDIA

We recommend that the Act includes a detailed section giving the NDIS power to engage in policy and service development in relation to disability and other mainstream service areas as well as the scheme's general operation.

At present, the Section 14 of the Act provides for the CEO to fund activities at his/her discretion. However, in moving to full scheme, the Act must provide for the establishment and operation of a policy unit with responsibilities for interface engagement with mainstream programs; as well as a service development function and capacity to review funding provisions for participants. At present, the lack of such a policy unit represents a major gap in the scheme design and one that invites the risk of cost blowouts because the NDIS has no connections or mandate to negotiate policy arrangements with other program areas.

The Alliance recommends the creation of a Policy Unit within the NDIA to undertake a range of functions including

- Cross Sector consultation and policy development
- Liaison with other government programs
- Price setting
- Provider management
- Quality and Safeguards monitoring
- Approval of providers and new services
- Conducting research and evaluations as well as curating evidence for scheme policy review and development.

3.1 Cross –Sector engagement and service coordination

The Act's failure to deliver a mandate to the scheme to engage in cross sector service engagement and policy development with mainstream and specialist programs, further hampers the opportunity to deliver significant mutual benefits to scheme participants, the NDIS and program partners themselves through such collaborative effort.

The Alliance has undertaken significant work in the area of cross sector service engagement; and development and delivery of integrated service pathways involving health, disability, housing and aged care services.[2] From this work, the Alliance strongly recommends that the NDIS Act incorporate a mandate for the NDIS to undertake proactive engagement and collaboration with mainstream and specialist programs to the mutual benefit of all stakeholders involved.

Many people with disability will require supports from mainstream programs to live their lives as citizens of their communities. The NDIS needs a legislative mechanism to provide capable cross sector coordination of these various services with the specialist disability supports funded by the NDIS to enable participants to achieve goals and service outcomes in mainstream sectors.

In recognition of the fact that participants will not live their lives in the specialist disability services system, and a capacity for cross sector service coordination is required, Section 31(k) needs to be rewritten to read (our wording):

> *(k) provide the context for the provision of disability services to the participant and, where appropriate, coordinate the design, procurement, delivery and continuity of disability and other services where there is a requirement for services from mainstream service programs.*

4. Early Intervention gateway

The Alliance believes that the early intervention eligibility gateway currently defined in S25 should be removed from the legislation. It is ill defined and would be made redundant through the practical application of the disability requirements in S24 and the emergence of the Independence, Linkages and Capacity (ILC) component of the scheme. Combined with the application of reasonable and necessary support for each participant, eligibility for the NDIS should suffice in implementing the scheme's model and delivering on objectives.

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[2] See YPINH National Alliance & Sydney University CDRP, *Cross sector service coordination for people with high and complex needs: Harnessing existing evidence and knowledge*, Sydney, 2014; and YPINH National Alliance, *Shaping the Future Today. Transforming Housing Policy for Australians with Disability*, Melbourne 2014.

Many ‘early intervention’ services required by adults with an disabilities acquired from brain or spinal cord injuries, progressive neurological conditions or disabling auto-immune diseases are not disability services, but services located within the health portfolio.

A key example is the need for rehabilitation that people with brain and spinal cord injury have. Generally located in the health system, rehabilitation is an early intervention service to support a person’s recovery of independence to the best of their capacity. At various stages of the rehabilitation pathway, both health and disability services will be required to maintain momentum around recovery.

From a health viewpoint and in the majority of cases, early intervention simply means clinical (sometimes inpatient) rehabilitation services. Yet it is widely recognised that the slow stream rehabilitation needed to assist individuals with acquired brain injuries, achieves best results when delivered in community settings.

For these reasons, rehabilitation has obvious interfaces with independence supports in the disability services area. As demonstrated by Victoria’s *Slow to Recover Acquired Brain Injury Program*, slow stream rehab delivered in this way is a cost effective, long term commitment to recovery that combines clinical services and capable disability supports over many years.

Rather than being “early interventions”, the disability supports these groups are likely to need are simply necessary service interventions. Their description as “early intervention services” under the Act is misleading and should therefore be removed.

With regard to early childhood therapy intervention, the Alliance believes that the current arrangements for early childhood intervention services should be split off from the NDIS and reconstituted as a separate companion (no fault) scheme with goal based planning and funding strategies, based in the health system.

Re-creating a separate scheme would maintain continuity for existing participants and serve as a signal that this sector is not being ‘cut’ by government. Importantly, this would also redefine this therapy based early intervention as a developmental health service, not as a disability service.

A link thus needs to be created between this new scheme and the NDIS to ensure that children who do satisfy the eligibility criteria under S24 of the NDIS Act, have continuity between their developmental therapy program and their required disability supports to ensure that as they grow and develop. Similarly, continuity and practical interface arrangements need to be put in place for these child participants with education systems.

The recent blowout in numbers of South Australian children diagnosed with autism spectrum disorders seeking admission to the scheme, is emblematic of an unintended consequence of the NDIS Act in its current form that, where no other options for early childhood therapies exist, a funnel is created into the scheme for families needing this service. This unintended route into the NDIS creates not only a risk to the scheme, but also delivers identity issues for families and children by entrenching the notion of disability very early in their lives.

As well as a blow out in numbers with potentially adverse consequences for the scheme's fiscal sustainability over the long term, bringing children into the scheme at such early points in life:

- Forces an identity of disability on children and their families far too early in a developmental process where delays may resolve as the child's development progresses.
- Creates a stigma that can become permanent though into education and later life.
- Encourages parents to seek a diagnosis of a condition as the only means of accessing developmental therapies, a path that can lead to future needs inflation for the scheme and for the child.
- Establishes the NDIS as the only funding source for therapies that should be delivered primarily by the health and education sectors.

In as much as rehabilitation is an early health services intervention that has complementarity with disability and other services over time, so early childhood therapy is primarily a health intervention that can be complemented by education and disability services over time. These areas of service delivery are thus not primarily about disability services. Yet locating these service areas in the NDIS warps their definition and allows disability to become the dominant service paradigm, creating in the process a strong barrier to integration between the various sectors.

The current definition of early intervention in S 25 is flawed and is part of the reason that this section needs to be repealed. It contains the requirement that the scheme's interventions be proven to 'reduce the need for support in future'. This is something that clearly cannot be guaranteed by any person at a point in time. It is also the wrong measure of effectiveness for people with degenerative or terminal conditions, many of whom need timely interventions prior to the full onset of their disease to assist in maintaining independence.

This requirement also prioritises the financial needs of the scheme ahead of the benefit of the intervention to the participant. While these certainly need to be in balance in scheme design, the current wording does not strike either the right balance or the right intent.

5. Governance

5.1 Independent Board

The Alliance supports the retention of an independent board for the NDIS. The Alliance is firmly of the view, however, that the board should not be made up only of state/territory or Australian Government nominated members. As well as board members with expertise in managing insurance schemes, places must be available for people with lived experience of the areas covered by the scheme.

5.2 Independent Advisory Council

Given that the States and Territories are part owners of the NDIS, it is important that they have a structure where they can operate an engagement strategy that is formally linked to the NDIS.

Section 143 therefore needs to be amended to include provision for each State and Territory to have their own Independent Advisory Council (IAC) that can provide advice and other input to the NDIS Board.

The existing provision for the NDIS' IAC has been a positive part of the scheme design, with the Council undertaking important work on a range of issues that has informed the board about a number of key scheme imperatives. However, in moving to full scheme, the NDIS requires a much more comprehensive consultation and engagement framework than that presently specified in the NDIS Act.

As well as the jurisdictional advisory groups, provision should also be made for demographic advisory structures representing

- Aboriginal communities
- The National Injury Insurance Scheme
- Cross-portfolio mainstream programs (e.g. health, justice, education, transport, housing)

6. Participant plans

6.1 Statement of Participant Goals

At present, Section 33 of the NDIS Act requires a statement of participant goals and aspirations to be developed as part of the planning process.

The Alliance believes that, on top of legislated eligibility criteria, developing this statement is an unreasonable expectation and should be removed from the legislation altogether. No other public funding program for individuals requires such a personal statement to be made in order to qualify for support. Participant goals and aspirations statements contain goal based thinking that is required in the planning process, a process that can respond to individual goals and aspirations more thoroughly over both the short and long terms.

6.2 Plan Reviews and changes

To be most effective, planning and the resultant plan must be dynamic. The requirement in Section 47(2) to have a new plan every time circumstances change is onerous for all parties and a costly as well as ineffective way of delivering the desired outcomes a participant may have identified.

A 'rolling' plan that can respond to changes in a participant's health and wellbeing, needs and life circumstances in a timely manner; a plan that can be updated and reviewed as needed, is more practical and effective. Such a plan can also be easily described in the legislation.

6.3 Choice of Planner

The Alliance believes that NDIS participants need to have choice of planner to undertake their NDIS plan. The Alliance has worked with scheme participants with acquired disability and complex needs who have expressed a strong view that they would prefer to have a content expert in their diagnostic area undertake their planning, rather than a scheme employee.

Given the need to do cross-sector planning and liaison to establish comprehensive support for YPINH, the planning function is much better done where there is not only expert diagnostic content knowledge, but also strong connections into other mainstream sectors such as health and aged care for the YPINH group particularly.

Choice of planner must specified in S 32A of the Act and, in turn, reflected in the rules.

6.4 Plan Management

Section 43(3) should be reworded to expressly exclude disability service providers from being plan management providers as well as service deliverers to NDIS participants. This is a fundamental conflict of interest in the design of the scheme and although this was included as a transitional measure for scheme launch, it is now time to remove this capacity from the Act.

7. Building a structured relationship with the community sector

Building a structured relationship with the community sector was an important feature of the Productivity Commission's 2011 *Disability Care and Support* Inquiry Report, emphasised particularly chapter 4.[3] The original drafting of the NDIS Act assumed that a market based response to the scheme and its participants would be enough to enable achievement of participants' objectives. This Alliance believes this was a very limited view.

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[3] Productivity Commission, *Disability Care and Support* Inquiry Report, Canberra, 2011: 201.

The Act did not provide any definition of either the market or the non-market responses that needed to be in place to achieve scheme objectives. However, after 2 years of operation, it has become clear that these segments need to be defined more clearly in the next version of the Act.

The non-service providing community sector has a key role to play in enabling the social and economic participation of people with disability in Australia and thereby assisting the NDIS to achieve its stated objectives. But other than direct service provision, there is no way of doing this under the current NDIS arrangements.

With the emergence of the Information, Linkages and Capacity building Framework (ILC), this definition of the key role the non-providing sector can play in supporting the NDIS, is now a fundamental requirement and must be fully included in the legislation.

The Alliance has long been advocating the definition of the role of non-providing community organisations in the Act, calling these essential entities Community Living Organisations (CLO).

To ensure that people obtain what they need from a range of mainstream and specialist programs, these CLOs will have complementary capacities to undertake cross sector linking and service coordination as part of their brief. Viewing 'early intervention' in this way would thus enable a more dynamic approach to the notion of 'reasonable and necessary' that involves actively looking for a range of supports from mainstream and specialist programs as well as those available in the ILC segment of the scheme.

Funded through the ILC, Community Living Organisations, could successfully undertake this critical critical triage activity, supporting scheme participants and the NDIS itself, to achieve their separate but complementary aims.

Benefits such as home and vehicle modifications, as well as one-off capital items that provide supports to keep people living well and independently, must also be named in this section as benefits available to people both in the ILC segment of the scheme, as well as those in Tier 3. In saying this, the Alliance believes it is important that the NDIS is responsible for capital modifications for people under 65.

Expanding the definition of early intervention allows the benefit of investment in early intervention activities to be available to scheme participants with progressive neurological conditions like Multiple Sclerosis, Huntington and Parkinson's Diseases, as well as participants living with spinal cord injury, acquired brain injury and mental illness. By enabling early intervention for these groups, the NDIS may enable people to variously maintain improved independence levels; remain in employment longer than otherwise possible; slow disease progress; and maintain family units and the informal supports families willingly provide for longer periods.

This requires the inclusion of a separate chapter in the Act that reflects the content of Chapter 4 of the Productivity Commission's report and also a substantial revision of Section 14 in regard to how the scheme can fund community organisations.

8. Other Matters

8.1 Registration of Providers

The Alliance strongly recommends that Part 3 of the Act be amended to require all providers receiving funding through NDIS plans to be registered and subject to indicative standards and active scrutiny. Different rules should apply to providers of personal services than those that need to apply to the purchase of capital items and consumables requiring different checks to monitor quality and price. However, regimes for both market areas need to be in place for all packages, whether self managed or managed by the NDIS or a Plan Management Provider.

8.2 Reasonable and necessary Services

The definition of Reasonable and Necessary is an important feature of the NDIS, and is based on the same principle of 'reasonable' that is contained in other no-fault insurance schemes in Australia.

Having a broad requirement of reasonableness is the essence of how the NDIS will deliver on its objective to meet individual needs. The discipline and work practices related to how the concepts of reasonable and necessary support are negotiated, is in fact the modus operandi of the scheme, and the point at which the tension between scheme viability and meeting individual need is mediated.

In the Alliance's view, the requirement to formally consider whether a support is more appropriately funded or provided through another area (Section 34 part (f)) has been problematic and is difficult to apply in the planning context without policy level protocols making this clearer for planners.

Other provisions in the Act need to define how this interface between the NDIS and other funding programs is worked out, as much of it relies on cross government protocols and agreements that are currently not in place at this stage of the scheme's evolution.

Relying on planners with limited understanding of the dynamics of service policy and provision in other service sectors and located inside the NDIS, is totally unreasonable and can lead to poor decisions. These planners and their line managers are not in a position to recognise gaps in service sectors or the politics about social reform.

The recent Administrative Appeals Tribunal decision on chiropractic services is a case in point.[4]

The other problem with part (f) is the reliance on the reasonable adjustment test in the Disability Discrimination Act (DDA) in (f) (ii). The DDA is about testing discrimination, not about defining practice in mainstream service delivery, or indeed access to services more generally. Section 34 cannot rely on a planner's interpretation of the DDA as it relates to future service use in the community by an NDIS participant.

In the Alliance's view Section 34 can remain useful with the omission of part (f) and so we recommend it be removed.

8.3 Reviewable decisions

The Alliance supports the external merits review system for NDIS decisions.

8.4 Eligibility for the NDIS

The current age cut-off of 65 years for eligibility for the scheme is problematic as it draws an arbitrary line that denies services to many people with a genuine need for support and no other program from which to get the specialised services they need. In particular, people with progressive neurological conditions that manifest after the age of 65, such as motor neurone disease and Huntington's disease; as well as those acquiring brain and spinal cord injury after age 65 fall into this group.

This anomaly has been well covered in the media. But given that the specialised services that this group needs are not available in aged care, a major equity problem exists in the NDIS reform as it currently stands.

Rehabilitation and lifetime disability supports are available in most no fault injury schemes for people catastrophically injured over 65, so to not have this matched in the NDIS is of clear concern, as it will effectively shift major costs to state and territory health systems as well as to aged care.

9. Further contact

For further contact regarding this submission, please contact

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[4] See https://billmaddens.wordpress.com/2015/08/25/ndis-chiropractic-treatment-a-reasonable-and-necessary-support/ Accessed 16 October 2015.

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