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Dear Mr McKeon AO

Subject: *Strategic Review of Health and Medical Research*

Thank you for considering our response to your *Consultation Summary* of your *Strategic Review of Health and Medical Research in Australia*.

The Consultation Summary's *Executive Summary* says that the Panel's vision includes "social goals such as equity, affordability and quality of life". The Panel wants to ensure "all research activity is well managed to deliver health impact". It says, "Initially, the focus should be on spending current investment more effectively".

The goal must be more ambitious than just "to deliver health impact". Government and the community need a qualifying adjective: health and medical research activity should deliver *maximum* or *optimal* health impact; at least *improving* impact.

Effective management of national health and medical research requires measurement and reporting of the health impact of research. So deciding how best to measure and report health impact must be an immediate priority.

The review strategy discusses the need to "set and support research priorities". It says, "the purpose of HMR is to improve health outcomes" and lists four strategic areas.

The Consultation Summary does not say why the four priority areas are chosen; they appear to be three that are politically motivated (possibly based on perceptions of equity) and one with a technology focus. If the goal is to *maximise* or *optimise* the health impact of HMR in Australia, the strategy should aim to better align research effort with measures like the "burden of disease".

In 2007, the AIHW published a report on "The burden of disease and injury in Australia 2003"¹. Some such measure of the significance of diseases and disorders must be central in setting research priorities and resource distribution to increase prospects for improving health impact/outcomes. Surely, evidence-based priorities and resource allocation are crucial to "well-managed research activity"

¹ <http://www.aihw.gov.au/publication-detail/?id=6442467990>

and in setting research priorities (and in management processes to ensure outcomes based on the priorities). We agree with 4.1 in your summary: “investigator initiated” research is important but a portion of the available resources should be directed to “the most promising research directions”.

We are concerned that the “burden of disease” measure ranks autism highly but there is very little autism research in Australia². The number of children diagnosed with autism spectrum disorders in Australia doubles every five years so the rating based on 2003 data is a serious underestimate of the current impact of autism in Australia. And autism research is minimal in Australia.

Currently most Government funding of autism services and support is for early intervention that has been classified as “based on emerging or best practice evidence” rather than funding treatment “based on established research evidence”³. Despite its growing significance, the chronic lack of relevant research has not changed in over a decade. This appears to be an issue for other “mental disorders” as well.

It seems most of the priorities recommended in your review relate (appropriately) to equity goals. This is morally and politically acceptable. We suggest your recommendations could take this further.

People with a disability, and people with autism spectrum disorders in particular, experience some of the worst outcomes⁴ of anyone in the country but there is little measurement and reporting of health outcomes for people with a disability in Australia.

Laudable goals like “equity” and “quality of life” are long-term health outcomes that encompass disability, the largely neglected (even ostracised) sibling of health services. We are disappointed that this review ignores “disability” at this time when the Federal Government’s focus is on equity and quality of life through programs like a National Disability Insurance Scheme.

Note that recent estimates of the scale of the disability sector suggest the need for at least \$18bn per year, yet there is no discernible research strategy and plan relating to “disability”. Surely, at least 3% of disability funding should go to strategic and well-managed research. Health and disability research might be better integrated.

² there was a substantial increase in funding for autism/ASD-related research in the latest NHMRC grants, but funding remains proportionally low.

³ see the Early Interventions Table (download http://www.fahcsia.gov.au/sites/default/files/files/disability-and-carers/hcwa_tables.doc, link is under “eligible intervention” at <http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/helping-children-with-autism#4>) or Prior, M., Roberts, J. M.A., Rodger, S., Williams, K. & Sutherland, R. (2011). *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders*. Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Australia (download from http://www.fahcsia.gov.au/sites/default/files/documents/09_2012/review_of_the_research_report_2011_o.doc).

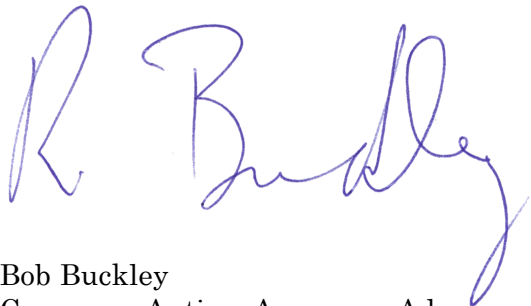
⁴ see <http://www.abs.gov.au/ausstats/abs@.nsf/PrimaryMainFeatures/4446.0> and <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4428.0Main+Features12009>

Australia ranks worst for poverty of people with a disability in the OECD⁵. Given Australia's abysmal record, governments should recognise Australians with a disability get little benefit from research funded through philanthropy.

Governments in Australia refuse to fund a peak body for autism so there are few resources to respond to "consultations" such as this. While many health and disability interest groups are funded to contribute to consultations, Governments in Australia leave it to the exhausted families and carers of people severely affected by autism to argue the case for increasing autism research.

We hope this perspective helps.

Yours sincerely,



Bob Buckley
Convenor, Autism Aspergers Advocacy Australia

31/10/2012

This submission is also endorsed by Speaking Out for Autism Spectrum Disorders (SOofASD): <http://sofasd.org.au/>

Conflict of interest statement: *Bob Buckley is Convenor of A4 and Chair of SOofASD, organisations that have never received funding for research and do not plan to do so in future. Bob has helped promote and decide on the recipients of several small grants for autism research. Bob is involved personally (employed) in bioinformatics research and services in the Genome Discovery Unit at John Curtin School of Medical Research, Australian National University. He also has a son (21 years old) with severe Autistic Disorder. He has never received funding for autism research, though he maybe involved in seeking research funding for autism research in the foreseeable future.*

⁵ <http://a4.org.au/a4/node/426>