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Att: Roberta Bausch

PERSONAL RESPONSES TO THE KEY QUESTIONS BEFORE THE PRODUCTIVITY COMMISSION'S INQUIRY INTO LONG-TERM DISABLITY CARE AND SUPPORT

The following comments represent the personal responses of a Valued Independent People Board sub-committee convened to discuss the issues. Those individuals on the Sub-committee are Syd Borman (Chairman), Richard Diermajer (Vice-Chairman), Marian Cross (Treasurer), Joan Martin (Secretary) and Sue Meredith (Board Member). All members of the sub-committee have severe or profoundly disabled children.

6. Who should be eligible?

Who should be in the new scheme and how could they be practically and reliably identified?

- Individuals who have been diagnosed at birth or within the first year of life as having the potential for severe or profound disability (including congenital anomalies and cognitive disability). Identified by neo-natal paediatricians, general practitioners and/or paediatricians.
- Individuals of pre-school age who are recognised by health professionals (general practitioners; paediatricians; child health workers who would need to refer the child to a general practitioner or paediatrician; occupational therapists, physiotherapists, speech pathologists) as having global developmental delay including physical and/or cognitive disability.
- School age children who have significant learning disabilities that require professional intervention or significant additional educational assistance in order to reach their potential. Teachers in conjunction with parents/care givers would initially refer these children to the school assessment service. (This covers the situation where disability has not been picked up at the pre-school age but where a period of intensive therapy or intervention will assist the individual to "catch-up" and thus reduce the need for later funding support.)
- People suffering from catastrophic injury, but are not able to get assistance through litigation and are not covered by any existing medical, workplace, motor vehicle or other insurance scheme should be eligible for the disability insurance scheme.
- Disability caused through nervous system disorders lasting more than 6 months.
- Other physical conditions lasting more than 6 months.

Notes: 1. FaHCSIA's criteria for providing carer allowances for care of children with a disability which depend on several overlapping classification approaches should continue to be used as a useful tool for determining eligibility.

2. We believe that the “severe or profound” classification is not always appropriate as early intervention, where a lesser degree of disability applies, can have large returns and great implication for future funding requirements. This also applies to individuals who require a small amount of support in order to achieve a better quality of life.
3. We do not believe that “an expectation that a disability would only last for a short time” should exclude a person (classified by a given definition as having a severe disability) from the scheme. Rather, when, or if, the person improves to a point where they no longer face specified core limitations, then insurance payments should cease following a rehabilitation process that sees the person reintegrated into suitable self sufficient employment. While there might be some risk that characterising people with shorter-term core limitations as disabled might prolong recovery and rehabilitation there is greater risk in not providing adequate funding to assist their recovery. Most of the costs of short-term disability should be covered by Medicare.

4. Regional versus city needs to be taken into account with regard to the level of payments. Where there are no services available in regional areas then greater funding through the insurance scheme needs to be made available so that necessary travel and accommodation costs can be met when the recipient and carer need to visit providers in regional centres or cities. Again, greater level of funding would need to be available where general disadvantage is combined with disability such as in some Indigenous communities. The PATS Scheme in WA and the NT is a good model.

5. Carers’ needs with regard to respite need to be factored into the scheme. Parent’s of severe or profoundly disabled children should from birth, or at a later time of their choice, be entitled to respite which is funded for one weekend in four and one-three week block respite per year. Due to lack of existing respite locations this could well-be funded in-home respite but for the well-being of the carer more out-of-home respite places need to be created. This will assist the mental health of carers. It should be noted that in cases of severe or profound disability the family’s income is affected in that one parent can not go out to work as they provide full-time care for the person affected by disability. This also has life long ramifications as that person will have little or no superannuation to help fund their retirement.

6. Because the eligibility process needs to be consistent, fair and transparent there must be an appeals process which is readily accessible with the cost born not by the individual or his/her supporting carers but by a Government agency.

What about natural ageing?

- We agree with the Issues Paper that the national disability scheme should provide support for people of **all ages**, so long as the disability was acquired before age 65 years (or in future in line with the new age pension qualification of 67 years). We do not believe that there is a problem with having two parallel funding and service management schemes – the aged care system and a disability insurance scheme even if the services may sometimes be delivered by the same providers. While some age-related conditions might and do occur before age 65/67 years, the grey area where these develop post 60 years of age, could well be problematic and while supported by the aged care sector could still be funded from a disability insurance scheme. If the disability related to natural aging occurs post pension eligibility age then costs would fall under the aged care system.

Comprehensive versus narrower coverage

As the proposed disability insurance scheme is a national scheme funded through taxation part of its appeal to the general populace would lie in the premise that, should the need arise the scheme stands in the existing gap and will fund their requirements. However, the assessment process and the fact that disability needs to be seen to last for more than 6 months automatically narrows the field. Support would need to be graduated to the level of need. With regard to disability arising from injury the national disability scheme should stand in the gap after other insurance avenues and/or litigation have been exhausted.

Application to new cases versus all people with existing disabilities:

- One of the problems with the existing system is the two tiers of funding from both Federal and State Governments. At the moment many essential services are funded through the State system which in turn is largely supported through Federal funding. However, this makes it very difficult, if not impossible, for families to move Inter State if their circumstances change. Examples of this are accommodation services and alternatives to employment. A National Disability Insurance Scheme is just that, national. As such people with existing disabilities would need to be included in the new system. This however, would need to be gradually implemented over at least a five to ten year period with existing Government funding boosting the coffers of the Insurance Scheme as existing funding recipients are moved from the present system to the new system. The new system does not abrogate the Government's existing responsibilities and need for funding for many years to come. The level of taxation applied to fund the Scheme needs to meet not only new claims but also build a pool for future claims.

- An alternative approach is that existing recipients continue to receive their funding under current Government methods. This would continue to be CPI indexed. However, changed circumstances would see their new additional needs being funded through the Insurance Scheme. This would result in some people receiving funding from both the existing scheme and the new Insurance Scheme. Provision would need to be made for existing recipients who need to move Interstate.

To what extent should eligibility include people experiencing short-term disability (7 to 12 months)

- Most of the needs of people who have a short term disability are met through the current Health Scheme and should be funded by the proposed National Disability Insurance Scheme.

How often should eligibility be re-assessed?

- Where developmental problems emerge the child needs to be assessed with on-going monitoring on an annual basis until the condition has been established as being a permanent, or likely to be permanent, severe/profound disability. This assessment would be undertaken by health professionals. On-going re-assessment in order to obtain funding through the National Disability Insurance Scheme should not be required thereafter. If the classification is severe or profound then it is a life-time classification and would only need to be re-assessed if needs change. If needs do change then the person/carers should be able to apply to the National Disability Insurance Scheme for reassessment.

- Where pre-school aged children are assessed as having global developmental delay they should be assessed annually until they either reach a point, through early intervention, where they no longer qualify due to improvement or have moved to a bi-annual assessment due to on-going need.

Should eligibility take account of people's income or assets?

- We do not believe that the scheme should be means tested any more than Medicare which is also funded through direct taxation is means tested. This is not a pension scheme but an insurance based scheme. Means testing is a disincentive in attempting to rejoin the work force as higher earnings from working would disqualify recipients from ongoing support whereas we should be encouraging workplace participation. There is also the argument that those who are earning the most are paying the highest premiums through taxation so why should they be disqualified if they are unfortunate enough to require payment from the insurance?

7. Who makes the decisions?

- The method in Western Australia where individualised funding has become the norm works pretty well. For those parents whose children have cognitive disabilities and who need to make decisions on their behalf they can choose to manage the funding for their child themselves or arrange for an agency to handle the funding on their behalf. One of the dangers of only having self-funding as a model is the potential for mismanagement and wasting funding. Even those not suffering from cognitive disability might not have the capability of making well-based choices and for that matter neither may their carers. The Local Area Co-ordinators through DSC in Western Australia have proved to be an adequate advisory system for carers. We believe that a panel approach to approving the funding plan is important. This would involve the person with the disability (provided that they have the cognitive ability to do so but their attendance and input is nevertheless to be valued), the main care giver/s, the LAC or equivalent person from DSC, and one or more persons from the service providers involved in formulating the funding plan. It is important that parent/carers are involved in the funding plan to help minimise tensions over the use of funding (for example respite services for the carer). There needs to be a clear list of services that are considered to be an appropriate use of funds. For example, personal spending would not be funded through the Insurance Scheme but from the individual's Disability Pension.

- Accountability is essential with a quarterly statement of how the money has been spent. Appropriate documentation would need to be retained for random audit purposes but not sent with the return. Similar to completing e-tax this could be designed for online completion although a hard copy option should remain available for those individuals who are not computer literate or who cannot readily access online facilities. Service providers would need to forward statements to individuals to assist the process. For those individuals, or their carers, who feel that this level of accountability is beyond them they would have the option of their service provider/s being responsible for their funding and completing the necessary quarterly return. A quarterly return would be of a similar time frame to a BAS which ensures that accounts are kept up to date. These returns would be monitored by the Disability Insurance Office or sub-contracted to the State Disability Service Commissions. It is very important that individuals can exercise some measure of control over the services that they receive. Equally important is accountability. We do not believe that people should be able to treat funding as ordinary income (that is what the Disability Pension is for). It could compare to the WA Shared Management model.

- As a principle, primary carers or other family members should not just be able to dip into the funding to pay themselves for providing care: that is the purpose of the Carers' Pension and Carers Allowance. However, when the funding plan is established an hourly rate for care could be an option. This would result in government saving in the area of the Carers Pension which is means tested. This would be particularly relevant in rural and remote areas where service availability is poorer. There needs to be a policy on employing/paying family members as per the WA DSC Policy.

- Any funding plan needs to have the CPI applied on an annual basis. This increased level of funding should be covered by the increased amount of “premiums” paid by increased wages. If at the end of the financial year a recipient has not used all of their funding then there should be provision for this to roll-over to save towards future additional services. If the funding has to be returned to the Disability Insurance Commission then this is a disincentive to saving and could result in wasteful spending to simply use up the allocation before the end of the twelve month period. We disagree with the concept of borrowing from future payments to pay for current services.

- There should be an annual review of funding plans, not so much for accountability as that would be done quarterly, but to review and update the plan for the forthcoming twelve months. If needs have changed this would be an appropriate time to lodge an additional “claim”, supported by professional documentation.

- In order to minimise the impact of individualised funding on service providers once the individualised annual funding plan has been formalised, each service provider could be paid directly on a quarterly basis by the Disability Insurance Commission. Quarterly statements would be sent to the client who in turn would use these in their quarterly reporting. Service providers would still be accountable to Disability Insurance Commission or its agent such as DSC in WA for all income received irrespective of the source.

8. The nature of services

- An area of great need and also great cost is respite and accommodation services. Better access to respite would improve the health of carers which in turn is cost saving. All parents of children with severe or profound disabilities live with the fear of what will happen to their child at their own demise. There is huge unmet need in this area and this must have a high priority in allocation of funding in any Disability Insurance Scheme. Obviously the predominant users would be the severe or profoundly disabled. The use of group homes by many service providers in Western Australia is an excellent model. When one is fortunate enough to eventually receive not only the funding, but a service provider as well, the sense of relief over your child’s more secure future is profound.

- It must continue to be acknowledged that some severe and profoundly disabled people will probably never be able to find work in the community BUT they are part of the community and funding must always be available for alternatives to employment. This is an area that requires on-going high cost funding.

- Aids and appliances, home modification, personal care services, community access and support are all important areas for funding.

- Therapy and professional services by professionals with appropriate expertise dealing with the needs of people with disabilities must be readily available.

- There needs to be better care of people with severe disabilities who need to spend time in hospital.

- There needs to be better access to medical practitioners and specialists

- Again the model in Western Australia for service standards monitoring with respect to quality, outcomes and cost effectiveness should be applied to a national scheme.

- We believe that income support would remain in the premise of Centrelink through the Disability Support Pension. Included in this would be the current mobility allowance, taxi vouchers and rent assistance for those in group homes or in private rental. This should not fall under the premise of the National Disability Insurance Scheme.

- If the National Disability Insurance is not means tested this would increase the likelihood of participation in work and the community. The Commonwealth Rehab Services used to be useful in this area.

- Co-payments are very similar to means-testing. With insurance many pay a cheaper premium because they will pay an excess for claims. We do not believe that this would work with the Disability Insurance Scheme as "premium" payments would already be linked to income. The more you earn the more you pay and for that matter are able to pay. It is possible that some services could have an annual cap, which once exceeded would then involve personal contribution. This is ethically questionable as we are talking about the most vulnerable of our society.

- We do not see a problem with people being able to cash-out benefits from a basic service/appliance/aid and use it as a part payment in purchasing a better or premium service in the same area provided that they can account for their spending.

How should people's needs be assessed?

- We agree that assessment tools are critical in determining eligibility but as to their nature this is outside our experience. Relevant discussion would need to be undertaken with professionals currently working in the field. We believe that the assessment tools should be carefully designed to identify applicants who are over-stating their needs.

- As parents we would advocate the use of nationally consistent tools.

- We would envisage that GPs and specialist disability staff would be involved in an initial assessment which would be confirmed by relevant specialists. As this is a medical diagnosis professional assessment costs should remain under the Medicare system.

- Allowance for a second opinion/appeal must be built into the system. This would assist in gauging the accuracy of assessments as well as the performance of assessors.

- On-going health assessments would continue to be funded through Medicare.

- Individuals, parents/carers should be able to apply for re-assessment when changes in life circumstances occur.

- In order to comply with the Privacy Act, written permission to make data available to a range of service providers must be sought from the individual and/or parents/carers at the time of assessment.

Service coordination and linkages with mainstream services

- We do **not** believe that income support through the current Disability Support Pension and service provision through the proposed National Disability Insurance Scheme should be linked.

- The Insurance Scheme should provide funding for all areas of support including the current Continence Management Strategy currently funded through Australian Government funds. As a consequence the operation of the Insurance Scheme would free up current State and Territory funding for subsidies for purchasing aids and appliances. This would progressively eliminate the current State differences in how subsidies are structured.

- The fact that service provision funding would be linked to the individual through the Insurance Scheme would make portability, both intra and interstate much easier.

How should insurance arrangements for catastrophic injury link in with a disability scheme?

- This is outside our area of expertise and we believe that overseas and interstate models should be studied in order to formulate policy.

9. How much is needed?

- Economists need to be consulted to model this. It is outside our area of expertise.

10. Financing options

- Outside our expertise.

- We believe that it should be similar to the Medicare levy – imposed by a similar taxation method. It must be seen as being different to and separate from the Medicare levy. We believe that it **must** be independent of the Medicare levy.