Submission

As a single parent with a young adult in my care who is classified as being a high functioning downs syndrome it has been difficult having the time available to be able to put forward a submission as well as try and develop a support system and path (using government and NGO) to enable her to reach her potential and have the same opportunities and quality of life as her sisters since her mother died in 2008.

The major problems has been dealing with government organisations and having to justify and prove her condition and abilities when seeking assistance or support. This can easily be rectified in a scheme where those with long term or permanent disabilities are classified according to their disability. Physical or intellectual, high or low functioning can be graded which then gives a financial level of support for use to achieve the immediate and long term goals which are reviewed or audited to determine that deliverables are being met and efficacy of the individual plan. Instead of having to deal with government departments and government funded agencies in seeking help carers are able to approach agencies with a care plan of short and long term goals and know that the plan will be implemented because funding is directed to the person with the disability. The agency than charges costs back to the account of the person with the disability. There is an over reliance on financial accountability and not on achieving outcomes. Due diligence by the funding body ensures that plans developed for people with disabilities are achievable (within the context of that individuals specific need), complex plans developed with assistance of specialists within that particular field or disability and outcomes measured over certain timeframes to identify successes and cost effectiveness.

Because she has been classified as high functioning she has not had any significant support since she has left school. She has managed through the efforts of her mother to gain open employment, who then got an agency to assist, for a period of 5 years until a new manager improved company profits and his bonus by firing those with disabilities. The disability specialist employment agencies had not achieved any work for her prior to this or since.

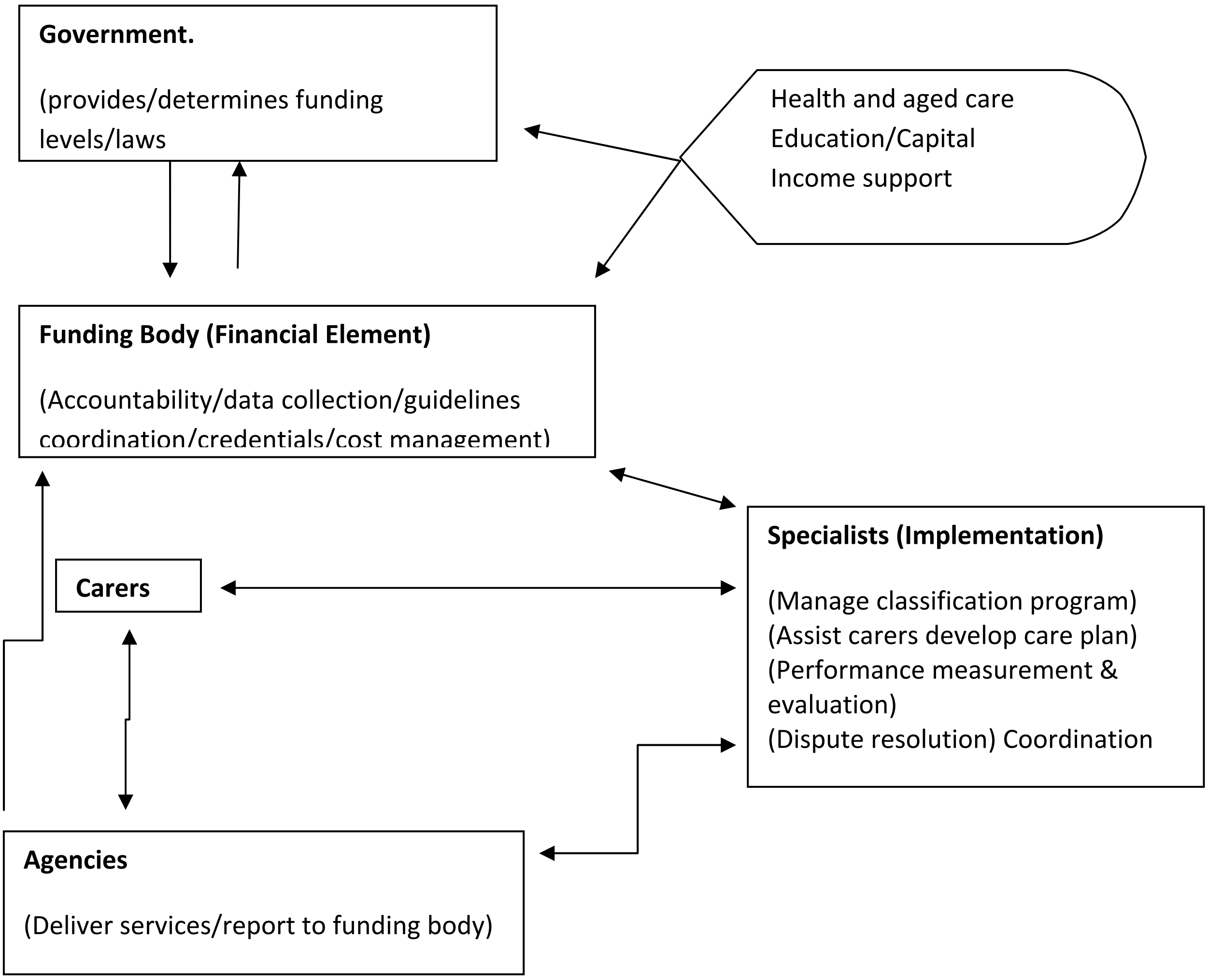
After a 6 month period in NSW I managed to get employment within a supported agency which does not make the most of her abilities or addresses her long term goals but because of funding through DEWR I cannot use an open employment agency unless I remove her from her current employment. This would then leave her sitting at home for another 3 months or so until the agency can find her work. Because the funding is through DEWR and Centrelink manages the referrals to disability employment agencies there is complexity which does not make for transition between agencies possible. The reporting and performance criteria is based on process and not outcomes, financial and not outcomes this makes it difficult to make changes as the carer see necessary quickly because of the reporting criteria and justifications. Repeating forms, medicals all make for unnecessary bureaucratic expense and carer stress. An open employment agency would not accept my daughter as a client until I had proof that her intellectual disability had her IQ below 60. This is established by the agency itself considering that DEWR does not yet have a criteria for determining the baseline for an agency to receive the 70% extra funding for high level disability under the new disability employment scheme. Just another roadblock in why it took over 6 months in dealing with state, federal and NGO to be able to get her level of disability recognised and getting a minimum level of assistance. However what has been achieved has been almost entirely through my efforts with minimum input from agencies apart from sending out forms or information. The agencies tell me as her carer what is required before assistance can be delivered, which is a farce, any system needs to have the major stakeholder as the one who has the power (within financial constraints of the system) and giving direction as they have the vision of what can be achieved and do the majority of work for financial loss. A carer can not hold down a job let alone build a career.

There would be a lag as carer plans determine specific program requirements, eg building and skills expansion to accommodate neglect within this sector of the community.

Transition to the scheme would be by determining baseline funding levels that is currently received by individuals (according to classification). There would be no reduction of service delivery but services would be lifted to those who receive assistance below required funding level. By initially determining current service delivery bureaucratic road blocks/red tape and duplication would assist in lowering budget expenditure and costing shortfalls.

Any scheme that wants to get people to participate in community and work and remove unnecessary bureaucracy is to take the financial accountability and authority out of the hands of the current arrangement of multiple government agencies and funding is between a single entity and the carer. Duplication is removed, delivery of services will be quicker and resources freed to enable an outcomes centric management of disability services. When it is established on the level of disability and the support resource plan coordination between agencies and departments is driven by the plan requirements and the carers and there is no need for any agency to have any authority. This integrated approach provides a whole of life because of the carers understanding of needs and not piecemeal results because of differing agencies requirements and funding shortfalls.

Flow Chart


Government.
(provides/determines funding levels/laws
Health and aged care
Education/Capital
Income support
Funding Body (Financial Element)
(Accountability/data collection/guidelines coordination/credentials/cost management)
Specialists (Implementation)
(Manage classification program)
(Assist carers develop care plan)
(Performance measurement & evaluation)
(Dispute resolution) Coordination
Carers
Agencies
(Deliver services/report to funding body)