Monday, 23 July 2012

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Ministry of Education, Special Education

Dear Mark

Thank you for the opportunity to review and comment on the Advisors on Deaf Children (AoDC) Development Project (Practice Framework) – a consultation document (DRAFT). It is good to have this opportunity.

We are both parents living in Wellington and we each have a daughter with bilateral cochlear implants.

We will make our comments using your feedback questions.

We would like to continue to be part of the consultation process on this project and would appreciate being added to the distribution list for future communications.

Finally we have also attached a copy of a parent's guide for new parents starting their Cochlear Implant journey. This has been written by a parent and might give you a taste of some of the issues that we as parents face.

Kind Regards

Sym Gardiner

Alice Henry

Question 1: What are the strengths of the proposed new practice framework in your view?

The strength of the proposed framework is that it seeks to remove some of the overlap between roles and shifts the focus of AoDCs onto the early years. It starts to recognise that being born deaf or hard of hearing no longer provides a limitation for a life time. For the majority of these children, there is a period of habilitation and then they are able to function without ongoing support. For those that need ongoing support there tends to be other medical issues compounding the deaf diagnosis.

Question 2: Can you identify any ways these strengths could be enhanced?

Yes. But these are better addressed in Qu 3 and 4. Please see below.

Question 3: What are the weaknesses of the proposed new practice framework in your view?

We believe that there are a number of weaknesses in the proposed new practice framework, both in relation to the foundations of the framework and other more specific issues. We have listed these below:

Foundations

- The framework does not recognise the differing skill sets required for the two core functions of an AoDC. One function is administrative – linking parents with service providers, pushing through resourcing requests, IEPs, etc. The other function is therapy or habilitation. The skills for each completely different.

- The framework does not recognise where the the best habilitation skills reside and does not align them to where they will make the most impact. In our experience, the best therapy or habilitation skills currently sit in the CI centres, followed by in some instances certain SLTs employed by GSE, followed by particular RTDs in the DECs and finally followed by some AoDCs. Yet under this framework, the AoDCs are being aligned at the most critical stage.

- The framework does not recognise that the mix of skills and experience required to support children and families can (and almost certainly does) change through the journey raising a child with a hearing issue.

- The consultation document does not explicitly address the lack of appropriate therapy or habilitation skills currently held by AoDCs. Nor does it recommend a pathway to address this lack of training and skills in AoDCs. We understand that over 90% of parents of deaf or hard of hearing (HoH) children are choosing spoken language as their childs sole means of communication. It is our understanding that internationally it is accepted that the most effective methodology to achieve this for deaf or HoH is the use of Auditory Verbal Therapy (AVT). There is no plan to recruit and/or train AoDCs in this methodology addressed in the document.

- The framework talks about memorandums of understanding and protocols to govern the sectors outside the AoDC relm. This has the potential to be useful and is probably necessary. However it has an organisational focus rather than a child centric focus. We fear the individual child's needs will be lost to the needs of organisations.

Specific Issues

- The allocation of responsibility for equipment such as FM systems misses an understanding that the technologies around hearing aids, cochlear implants and their support systems are becoming more and more technical and specialised. We believe that AoDCs and RTDs do not have the specialised technical skills that are required to properly support such technologies adequately.

Question 4: Can you identify any ways these weaknesses could be overcome?

We have outlined our solutions below, using the same categories adopted in question 3 above.

Foundations

- The role of the AoDC is too broad and requires skill sets that do not tend to manifest themselves in a single person. We believe that AoDCs should be given the option to operate in 1 of 2 different specialties, 1) AoDCs – Counsellor, or 2) AoDC – Therapist. The councillor role would be to guide families. The therapist role would be to provide high quality therapy, be that AVT or sign, at the formative stages in support of the activities of the DECs and/or CI centres.

- Those AoDCs specialising in the second of the two roles, AoDC – Therapist, should be strongly encouraged to train in AVT. This is a 3-5 year post graduate qualification. This could be done through scholarships, recognition of an AVT qualification in salaries and appointment of clincial leaders who are AVT trained. It may also be more appropriate to recruit AoDC – Therapists with more suitable backgrounds to train in this area.

- IEPs are the key mechanism for determining resource need and mix. IEPs are child centric and are utilitised across all special needs areas. They, rather than MoUs or protocols, should ultimately govern how the various organisations interact. For instance, for cochlear implant children and families the CI centres provide the majority of the linkages and co-ordination of services. They also provide the direction of the habilitation. AoDCs, SLTs and RTDs should follow the direction of the Habilitationists (who are the most qualified and skilled professionals involved with these children). However for the very small number of sign only children, the direction and linkages would best be driven out of the DECs. That is where those specialists reside.

Specific Issues

- The technical side of CIs, HAs and their support components are too specialised for AoDCs. In the case of CIs, the technical side (including associated technologies such as FM systems) should be managed by audiologists in the CI programmes, who are the technical specialists.

Question 5: In your opinion, what support would you or your organisation need to make the proposed new framework work well?

The new framework, as it stands, will make no difference to ourselves or our daughters. It doesn't improve anything. It doesn't create any new negative outcomes. So no support would be needed.

Question 6: In your opinion, what support would children and young people and their families and whānau need to make the proposed new practice framework work well?

As outlined above, the framework misses a number of critical issues currently impacting the deaf education sector. It is only looking at one small component of the sector and is not making any changes to address the critical issues. Therefore we believe it will not work well, as the current system does not work well.

Question 7: Any other comments?

We believe that the deaf sector in New Zealand is now significantly out of step from international norms (outside the Auckland region we are 20 years behind the Australian states). Universally it is recognised that intensive intervention as early as possible makes the biggest effect. However the NZ deaf education sector is still geared around long term low intensity support of children. This was appropriate when the majority of children were oral/lip reading or NZSL. However now with the advances in hearing aids and cochlear implants the vast majority (we understand this level to be over 90%) of children are now able to hear at levels that allow them communicate through spoken languages.

What these children need to catch up with their peers as quickly as possible is intense habilitation at as young an age as possible. The deaf education sector needs to be reshaped to pump in appropriately skilled and qualified resources at those young ages (not restrict them to later ages like the current restriction on RTD involvement to over 3s). And the sector needs to significantly upskill in more modern and effective habilitation approaches to do this.

Until this happens, the tinkering around the edges will not help those it should – the children. It will just provide employment for people who we are sure are genuinely passionate about the children they work with, but are sadly underskilled and currently incapable of providing the services that these children need.