

Severe speech and language difficulties in school aged children from language unit and mainstream settings:

A qualitative study of parental experiences

Kelly Fraser and Suzanne C. Purdy

Speech Science, Department of Psychology (Tamaki Campus), The University of Auckland

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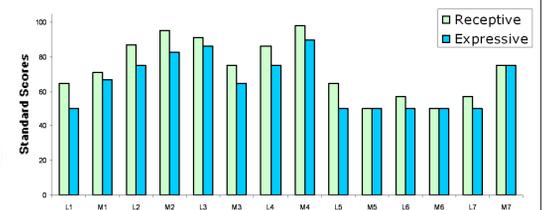
Experimental Question

What are the experiences of parents of children with severe speech and language disorder?

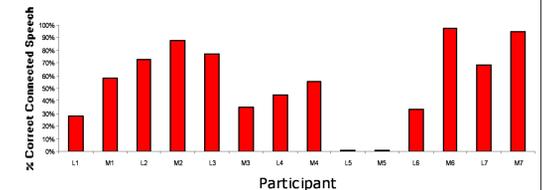
Methods

- Parent perspectives investigated using a qualitative research design.
- Conducted semi-structured interviews covering: first indication of difficulty, early intervention, diagnosis, school setting, and experience of school setting and support.
- Parents of 16 children participated. Seven children attended a language unit (mean age 7;03), seven children attended mainstream education (mean age 7;04), and two older children were in their final years of high school. Parents came from wide range of educational backgrounds.
- Children had a range of CELF expressive and receptive language and intelligibility scores, as shown in the figures.
- Interview transcriptions were analyzed using NVivo 2.0 software. All transcriptions were examined for content and sub-categories and coded by the researchers, prior to further thematic analysis.
- Thematic analysis was used to identify key patterns or themes within the data.

CELF Receptive & Expressive Language Scores



Speech Intelligibility



Themes Identified

| (1) seeking support during preschool years | (2) finding a best fit | (3) concern for the future | (4) dis/satisfaction with school | (5) access to support | (6) relationships | (7) finding a perfect world |
|---|--|--|---|---|--|---|
| "The kindy teacher couldn't cope with her... she came to me and said that she thought ...[child] had a hearing problem. ... I went through the rigmarole of getting her tested and they said that her hearing was perfectly normal... so we went through the private specialist and then from the private specialist we went to the hospital specialist. And at about the same time as we had the appointment with the hospital specialist, I managed to get her to [early intervention unit] ...we didn't know what the problem was." (L3) | "...we did look at the local school... and also [special school]... [child] was considered too advanced...sat in on a satellite class ...[child] was still slightly too advanced... went to [local school] and they just didn't really have the resources, they were way away from any facility for special, for low level special needs. And [chosen school] when we went there, they were quite cool about it... [child] went for a visit for 2 weeks prior to starting school and we had two meetings at school with the teachers...Just to discuss all the issues, so they were prepared" (M5) | "...with a normal child you can plan basically what their pathway might be. And you've got some general drift of that they're going to go to this primary school and then they'll probably go on to this intermediate and this high school. Whereas these kids you have no idea. And that is really stressful on families. Really stressful. There is no pathway through the education system and I just can't understand why there isn't because there are so many of these kids." (L7) | "...she's not got the level of teacher input that would have been important I think in terms of progressing her educational skills...her specific needs haven't really been identified and addressed specifically... She wasn't getting support at school basically. We just felt that it wasn't the right setting for her and there was a lot of bullying going on as well ...they really have not had any special needs students there and of course there is little information and knowledge about verbal dyspraxia" (H1) | "You just get little blocks of time. You know you might get 3 sessions, 6 sessions and then that's it, you don't see them for a while...we're meant to have speech language therapy, but really you didn't see them for dust." (L1) | "...rely on each other a lot...the last four years, have been hard since we first realised that there was something wrong with ... you go through that whole grieving like a mourning process..." (M3) | "it would be very good to see a unit in between to take children that are 7 to 9 and sort of get them to be able to integrate and do the things that mainstream do but in a different way. There are things that people take for granted like knowing the months of the year and how to write the date and understanding little practical things that you don't often get taught. It's assumed that you just learn simply by being in class." (L4) |
| "We saw a child development team for physio when he was 18 months... a little bit later when he was 2, we started having a paediatric OT formally diagnosed at the age of three. ... we actually saw developmental paediatricians there...we went to go and see a speech therapist while we were there who...said that he had severe verbal dyspraxia. ...We then got a private OT ... we were very fortunate to meet a woman who was a speech therapist" (L4) | "I visited 14 schools...I was looking at moving her from this unit to that class here. But you had to be in zone we were quite prepared to move in zone to do that ... to try and plan what we're doing has just been, quite frankly, a complete nightmare. ...when I was looking for a school, nobody could tell me how many hours teacher aide she would get in the various schools...so it was a complete gamble basically. You can't look at a package and go, well in this environment she's going to get two hours speech therapy a week." (L7) | "...we think well maybe we should just concentrate on what's happening now and then see how he's going in a few years, maybe he will need to go to a special school..., go to a school with smaller classrooms...the real issues haven't started yet, it's when he starts getting to adolescence." (M5) | "...even though it's a communication class, speech therapy has always been lacking in it. ...So whilst all the learning was scaled back, the real core services that should have been provided, they actually weren't here...my concern is again the lack of speech therapy." (L5) | "...the system being as it is, and the lack of money... I think that it's fair what she's getting, I think that everybody is trying really hard... I mean it would be nice for [child] to have teacher aide but then I don't want her to rely on that as well... she had a teacher side at [school], just because her behaviour was very, very bad and I mean I know my daughter is a good girl but when she is not settled ...at the last IEP, the speech and language therapist said that...she's no longer in that bracket to get funding for, to actually have a speech and language therapist because she's not severe enough." (M6) | "And then we started in on speech therapy with [therapist]... She's been a very big part of [child]'s development. She probably knows her the best..." (L1) | "...actually think it would be great for him to have more teacher aide help...Maybe a small classroom, with just a few kids and then he could get more one on one help...Maybe a mainstream, or even kids with other disabilities in that classroom. But I think having a smaller satellite class, and having higher qualified teachers, more experienced teachers rather than qualified, is much better. So it's really about the committed teacher that can help." (M5) |

Conclusions

- All parents had some form of early intervention; this included a range of professionals involved in diagnosis or therapy. This suggests that parents understand the importance of input at this stage.
- No clear relationship was evident between the child's abilities and setting chosen. Mainstream was chosen based on location, first impressions, support offered and beliefs about the inclusion model. Language Unit was chosen based on recommendations from professionals and parents' opposition to mainstream education for their child.
- Most parents were unable to comment on their child's future as they were focused on the present. Those that did, felt there were limited or no options as their child progressed through school.
- All parents had positive experiences. There were more negative experiences, however, when parents were speaking about mainstream; these included lack of knowledge and negative attitudes of the school and staff.
- Many felt they were the sole advocate for their child when trying to access or increase services. There was some concern about the frequency of therapy, particularly as children got older.
- Parents felt that there were negative emotional, social and financial impacts on family relationships. However, they also reported positive effects on siblings and relationships with some professionals.
- Parents' descriptions of the ideal setting were varied. These included small class size, knowledgeable staff, visual supports, one-on-one, and repetition.

