

Evidence that we can change the profile from a study of inclusive education

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Abstract – This paper discusses the evidence that the specific developmental profile frequently described as being associated with Down syndrome – a profile of communication weaknesses relative to social and daily living skills – can be changed. It is not an inevitable outcome of having Down syndrome. Drawing on data collected to explore the outcomes of fully inclusive education for school-age children with Down syndrome, the authors identify that the profile is seen in teenagers in special education settings but is not evident for teenagers in inclusive education. They argue that this is the result of both the effects of fully inclusive education and teaching approaches which have been adapted to address the cognitive and communication weaknesses of the children from an early age.

Keywords: Behavioural phenotypes, Down syndrome, education, inclusive education, special education, communication, expressive language, receptive language, specific profiles, adaptive behaviour

There is a specific profile

The first two articles in this issue describe the profile of development that seems to be typically associated with having Down syndrome. In particular, the children tend to show strengths in social understanding and social development and specific delays in speech and language development over time. The Dykens, Hodapp and Evans paper shows this for primary age children, our data in the following article show it clearly for teenagers who have been educated in a special education classroom (see Figure 3 on page 57) and the Fidler, Hepburn and Rogers paper shows it emerging at the preschool stage. The benefit of knowing that this is the early profile of strengths and weaknesses is that we can use this information to design specifically targeted intervention strategies.

The profiles should inform practice in early years

In our work, we had realised in the early 1980s (see Buckley 1985) that the children understood more than they could express verbally and that they had strengths as visual learners, so we were signing with the children from the first year of life, working on listening and sound discrimination skills, encouraging sound production games and teaching vocabulary and sentences. We were aware that visual short-term memory is typically better than verbal short-term memory and were introducing reading activities to support spoken language development as well as to teach children to read. In the preschool years, we did all this work by showing parents how to use these strategies in their daily interactions with their children at home.

Development is social

Being strongly aware of the importance of learning together with typically developing peers for all children, we pushed for inclusion rather than segregation. A child needs other competent children for language models and language partners (you cannot learn to talk if your partner cannot talk), for role models for social behaviour and for learning behaviour in the classroom. Therefore, from 1988, we have placed the children with Down syndrome in our locality straight into mainstream, same-age classrooms with support, from 4-5 years of age. In the UK children start full time school at the start of the school year during which they will be 5.

The profile should inform practice in schools

Once in school, we have applied the information about the profile to adapting the curriculum and teaching methods to address weaknesses – using visual supports whenever possible, teaching reading and writing, using literacy activities to develop knowledge and spoken language, compensating for verbal short-term memory difficulties and engaging in some memory training. We have also used the children's strengths – good social understanding should enable children with Down syndrome to fit in and to be fully socially included. We encourage good social behaviour and expect children to learn and socialise in age-appropriate classrooms. This is important for their self-esteem, confidence and inclusion in clubs and activities in and out of school.

If we do this, we can change the profile

Here we reprint an article which shows the benefits of full inclusion for long-term development first published in *Down Syndrome News and Update* 2(2) in 2002.

We have added in the detailed data tables and statistics as appendices for the readers of this journal.

Population samples

The total samples for both the 1987 and 1999 studies were recruited by contacting all families with children with Down syndrome in the county of Hampshire, UK, through schools, physicians, social services and parent organisations. We believe we contacted the majority – between 95-100% on both occasions. In 1987, 90 of 108 (83%) families agreed to take part and in 1999, 46 of 60 (77%) families took part. The information that we have on the young people and the families who did not take part does not indicate that they varied in any significant ways from those that did. Some who did not take part were in mainstream schools and some were in special schools in the 1999 cohort.

It was only when we collected in the 1999 data for all the teenagers in the county to replicate our 1987 study that we realised we could compare the outcomes of the school systems and that school placement had significantly influenced progress. Full data on the samples is provided in Appendices 1 and 2 on page 63 and also the evidence that there were no significant differences on family variables between the groups.

It should be stressed that school placement was related to which part of the county the child lived in at the time. In the part of the county in which we work, full inclusion in primary education from 5 years started for most children with Down syndrome in 1988 but not in the rest of the county.

It should also be stressed that, in order to ensure fair comparisons, the least able 5 teenagers were removed from the special school sample (based on Total Vineland Adaptive Behaviour scores). The group of included teenagers studied also have a mean age 2 years younger than the special education group. This should have advantaged the special education group as we have improvement with age on almost all measures in both groups.

The data is striking and specific

One of the measures used in our studies, and the one reported here, is The Vineland Adaptive Behaviour Scale and this is the same measure as used in both the Fidler et al. and the Dykens et al. paper. The results of the Hampshire data are very striking – the weakness in speech, language and literacy has disappeared for the children in the more stimulating and normal social and educational worlds. They were also receiving interventions from early years and in school based on the evidence of the strengths and weaknesses in the early learning and developmental capacities of babies and children with Down syndrome.

The evidence contained in the following article shows that we can change the profile – it is not an inevitable consequence of having Down syndrome. The teenagers with Down syndrome who have been included in mainstream age-appropriate classrooms do not show a weakness in communication skills relative to their social and daily living skills – see Figure 3 page 57. The teenagers in special education show the expected profile, with significant differences between their communication, socialisation and daily living skills in the expected direction. The specificity of the gains in communication for the included teenagers is, perhaps, more striking as their overall socialisation and daily living scores do not differ significantly from those of the teenagers in the special school group.

There is no statistically significant difference between expressive and receptive language for the included teenagers but there is the expected significant difference for the teenagers in special education. The mean difference in expressive language is 3 months behind receptive language for the included teenagers and 27 months behind for those in special education (see Appendix 8, p.66).

Individual differences

Group data does not always reflect the patterns for each individual but in our mainstreamed group of 17 teenagers, only 3 (17%) individuals have communication skills lagging behind social and daily living skills. In our special school group 16 (73%) of the 22 teenagers show the significant lag in communication skills, and 6 show an even profile. For receptive versus expressive language scores, all 22 teenagers in the special school group and 11 of the 17 teenagers in the mainstream group have expressive language delayed relative to receptive language, while 6 of the mainstreamed group have expressive language scores ahead of receptive language scores.

Progress with age

The data in Figure 1 page 56 show that we do not see plateaus in development – there is progress by age group for all the teenagers regardless of school setting, except on communication. Those in special schools do not show progress with age on communication whereas those in mainstream schools do.

Support for evidence based practice in early intervention and education

This is evidence-based practice and it works. Most importantly, it highlights that we must remember that development is a social and transactional process over a lifetime. The danger of talking about profiles is that they may suggest fixed and unchangeable developmental patterns – especially when the cause of the disability has changed the genetic makeup of the individual. This data should be shared with everyone working in early intervention and education settings with children with Down syndrome.

We are about to document our early intervention strategies and embark on a longitudinal study to evaluate its effectiveness by recording progress in detail from birth to 5 years.

Support for inclusion

The final point in my argument is that we needed two changes to produce this outcome, according to our evidence. The children in the special schools in our study would have also had some of the same approaches in early intervention and in school, such as the use of signing and visual supports for learning, yet nothing changed for them (in fact they were doing no better than the group of teenagers we studied in 1987 before we had this knowledge – see the article).

Therefore, we need evidence based strategies in services which clearly take account of the specific profile of strengths and weaknesses which seem to be associated with Down syndrome and address them. Secondly, the children will only make optimal progress in inclusive environments. Historically the profile may have been as much the result of limiting social and educational learning opportunities in segregated settings as not knowing how to adapt teaching and learning approaches.

Segregated classrooms can be worse than special schools

In some countries, self-contained classrooms in a mainstream school are passed off as inclusion. However, they may be even less effective educational environments than the UK special schools described in our studies. In the special schools evaluated in this study, children were in similar age and ability groups. In a self-contained classroom in a mainstream primary school we may have children from 5 to 11 years and of a wide range of abilities. This makes it even more difficult for the teacher to design and implement effective teaching for the individual children – and he or she lacks the competent role models for learning provided by typically developing peers. Often inclusion in these schools is mixing at break for drama, arts and physical education – this is not supporting effective literacy and language learning – that comes from the formal academic lessons.

A window of opportunity

This is very important data and it is probably not possible to easily replicate the entire study as, at the time these children went to school (1984-1994), inclusion was only just starting in the UK. We were able to take children of similar ability and family backgrounds in an area where they were still going into special school and compare them with a similar group living in our locality where we were one of the first areas in the UK to offer full inclusion in the neighbourhood mainstream school for children with Down syndrome. Now the majority of children with Down syndrome go to mainstream primary schools in the UK – only children with additional difficulties and more severe delays go to special classrooms, so it would no longer be possible

to compare long term outcomes as the children in the two educational systems are not of similar abilities at the start.

A need to replicate

However, we do plan to do further studies of included school-age children across the UK to see if they show the same benefits in terms of speech, language and literacy progress and the change in the profile – and to see how these benefits develop during primary years as, at present we only have teenage data.

In summary

To change the profile, this data suggests that we need both evidence-based adapted teaching and learning and we need full inclusion in the educational environment to change the profile.

Reference

- Buckley, S. (1985). Attaining basic educational skills: reading, writing and number. In (Eds.) D. Lane & B. Stratford. *Current Approaches to Down Syndrome*. London: Holt, Rinehart and Winston. Pp.315-344