

family

A D V O C A C Y

Education as a continuing state of being¹

Dr Bob Jackson

Education is often thought of as relating to school or post school formal education situations. The reality however is that from birth to death, human life is a never-ending stream of learning experiences, most of which occur outside of formal learning structures. In the first five years of life, under the tutelage of parents, a child learns faster than at any other time of life. Through later developmental years children learn complex social and societal skills and behaviours that ensure their community inclusion. In the workplace and life we learn a vast array of skills and competencies from our friends and colleagues. In this paper it is argued that if we study how this learning occurs, we find that children and adults with disabilities can learn these same skills and competencies and learn without limit all through life. However if we set low expectations; isolate people from peers and mentors; set artificial 'potentials'; engage a person in mind-numbing time-wasting activities, or fail to structure learning to the person's level, then failure becomes a habit.

It is widely acknowledged that it is an innate human characteristic to grow and develop. However, in the field of disability we hear words such as "reaching his maximum potential" or "She has an intellectual disability", where the 'dis' in disability is derived from the Greek root meaning death - so death of intellectual ability. Our history is full of even worse examples with labels such as 'mentally incurable', 'idiot', 'imbecile', and possibly the worst of all - 'moron' - which was short for 'moral imbecile'.

The very notion of IQ is based around the assumption that intellectual capability is a fixed quantity that is primarily genetically determined, is constant throughout life and not influenced by learning or changes in environment after the age of about 5 years. When I first did my training in psychology I was taught that children with an IQ below 50 were ineducable and those with an IQ less than 30 were untrainable. Those with an IQ between 50 and 70 could be taught life skills so that they could become productive members of the community. Clearly, any suggestion that such children could learn the academic skills of reading, writing and arithmetic was only worthy of ridicule, and trying to

¹ This paper has not been referenced academically as it is aimed at a family audience. If references are desired, please contact the author.

teach the ineducable or train the untrainable was of course a futile exercise. In this regard, I often find that not much has changed with much segregated education focussing on life and community skills with little regard to the normal academic curriculum so central to the education of all other children. Overall then, we have many examples of subtle and not so subtle messages that for people that we label in relation to physical or intellectual disability, the common expectations relevant to others do not apply. Basically they do not learn or develop very much, and any development will only be to some predetermined potential whereupon they are presumably expected to plateau.

In a famous but widely criticised study, an academic named Rosenthal went into a classroom of ordinary primary aged children and gained permission to test all of the children. He explained to the teacher that he had administered a test which could determine those children who were 'late bloomers', and who were likely to spurt ahead in the near future. He advised the teacher of the names of these children who were expected to spurt ahead. As he predicted, those children did in fact spurt ahead and the rest of the class stayed more or less the same. The only difficulty was that he had in fact selected the children at random – they had improved because of the teacher's expectation that they would improve. What is more, he had actually administered an IQ test on both occasions, so it was the children's IQ that had increased! This study caused a furore in the academic literature as it attacked the fundamental assumption that learning capacity is fixed and unable to be altered in any significant way by different interventions. However, it makes inherent common sense – "If I think you are like it and treat you like it then it is likely that you will become like it". While we all intuitively know this, even people with wide experience or parents who love their children and want the very best for them can be caught in this cycle of low expectations. With parents, it is of course much more understandable. It is very hard for any individual parent to withstand a room full of professionals saying that their child is inherently incapable and the skill gains that they see are a figment of their imagination. In my experience, it is a rare parent who can undergo repeated attacks on their child's capacity without some self-doubt creeping into their own assessments.

What then is the reality? The first point to consider in some detail is the role of intelligence, and in particular the IQ score. Going back historically, the first 'intelligence test' is normally credited to Galton, the father of eugenics. A nephew of Charles Darwin, he saw intelligence as an inherited characteristic that was susceptible to the new science of selective breeding "The best men must have intercourse with the best women as frequently as possible, and the opposite is true of the very inferior". The test that he devised was based on the assumption that the less intelligent were less susceptible to both pain and the influence of heat and cold – an assumption that led to institutions for the 'mentally defective' to be designed without heating or cooling into the 20th century.

Several psychologists attempted to devise a range of puzzles to test a general level of intelligence, and initially the most widely recognised of these was designed by a Frenchman named Binet

(together with a colleague named Simon). Many of you would have heard of the Stanford Binet Intelligence Test, which is still used widely to this day. Binet's aim was to design a test to find those children who were struggling at school so that they could receive additional help in order that they did not fall behind. Binet specifically stressed that this did not give an indication of any stable measure of intelligence and should not be used to stream children. Unfortunately, two academics named Terman and Merrill from Stanford University (hence the *Stanford* Binet) brought the test to America with the specific intention of using it to find those of limited intelligence so that they could be stopped from breeding using processes of segregation and sterilisation. At around the same time, intelligence testing was being used to restrict immigration to the United States as it was found that people who came from non-English speaking countries did poorly on an English language intelligence test. Others were using intelligence tests to show that Negroes were less intelligent than whites and women less intelligent than men – all of course by these new 'objective' measures.

The intelligence test was then fundamentally being used to find those that were of lower intelligence in order to segregate, and in some cases sterilise them. While sterilisation is much less frequent today, the use of intelligence tests as a reason to segregate people is still common, particularly in education.

What then are some of the assumptions of intelligence tests?

- Intelligence comprises a genetic component which can be decreased by environmental factors in the first five years of life, but after that it remains relatively stable. That is, a deprived environment in the early years can cause a drop in intelligence. However, the opposite assumption of increased intelligence in an enhanced environment is generally not made.
- The circumstances of an intelligence testing session are not likely to produce a major difference in IQ scores. That is, a psychologist can take an unknown child into a room for a one hour period and from that determine more accurately the child's potential than a parent who has known the child from birth.
- The clinical skills of the psychologist will overcome any problems with fear, lack of motivation coming from years of failure or just plain disinterest in the test. The fact that the only way to escape the testing situation is to fail sufficient items is not considered relevant.
- The intelligence test is a valid measure of the inherent capacity of the child.
- It is reliable – that is, if we test today and test tomorrow, we should get the same result.
- A low IQ score won't change expectations – it will just be used to provide an appropriate education program.

What then is the reality? It has been known for decades that intelligence test scores can be changed by quality intervention. Dr Alex Maggs, an inspiring academic from NSW took a wide range of

children such as children with Down Syndrome, Aboriginals and institutionalised children labelled as untrainable and taught them to read and write. In the early 1970s at Macquarie University in Sydney, a 'Down Syndrome early intervention program' was started that raised the intelligence of the children, in many cases to considerably above average. The great majority of this work was published but overall it seems to have had minimal impact on education systems and services as the prevailing paradigm is of incapacity and limitation as soon as a low IQ has been found.

In the UK, some interesting work has been going on with teaching children to read from very early ages – from as low as age 2 was reported at an international conference in Sydney. They reported that there has been some intriguing evidence that the number of synapses – or neural connections in the brain - increase as a result of this early intervention. Apparently, we are born with a huge number of potential neural connections – in fact at age 2-3 we are likely to have 3 times the number of synapses as our paediatrician. What occurs though is that if we don't use the synapses they fall into disuse and become inoperative. The theory then is that if we can use as many synapses as possible when the brain is developing we will retain a greater proportion. The implication is that a child born with an intellectual disability – and assumedly less synapses - may be able to hold a higher proportion through early intervention and so end up with less or no intellectual disability. In work that we did at Edith Cowan with children diagnosed as autistic, early indications are that this is possible. Taking children as young as age 2 (although more commonly aged 3 or 4 due to delays in diagnosis) we assessed the children and discovered that their baseline learning rate was in the region normally described as 'intellectually handicapped'. However, with the parents teaching the children under our guidance and with material supplied by us, we found that all children we were able to start on reading accelerated their development to ABOVE normal levels. That is, they started to catch up and in several cases moved into the normal range and out of the autism spectrum. Apart from learning to read (in it self believed to be impossible by many in the field) many of these children appeared to be increasing in 'IQ'. We did not test for this for reasons that should be obvious but the test that we used correlates with IQ and showed that this was in fact a likely outcome.

This then is the first stage in changing our attitudes: Children with the label of 'intellectually disabled', 'mentally handicapped', 'Downs', 'autistic' etc can in fact develop **faster than normal** and so can start to catch up. We have now achieved this with so many children that we use it as a measure of the success of our intervention – if the child is not learning faster than non-disabled children, then we need to re-assess our teaching strategies.

We also need to be appreciative of the teaching skills of families and not allow the enormous skill and potential in this group to be pushed aside by assumptions that professionals will be able to do it better. We know that children learn at a faster rate in the first 5 years of life than in any equivalent 5 year period. Who are the teachers? Parents of course. Who is more likely to be successful – a

therapist or psychologist who spends the occasional hour session with a child or a parent who devotes up to 5000 waking hours per year to their child's education? This is not to deny the skills of professionals – we do learn a lot in 4 or more years of dedicated study - so professionals are worth listening to. However, let's not get carried away with wished for magic professional bullets to development when highly skilled resources to teach are available in every family.

Why are parents so good at teaching? Just watch a parent teaching a child to catch a ball. The child's arms are held out ready, the parent rolls a big light beach ball into the child's waiting arms and effusive praise is administered. Gradually, the parent moves further away, the child is instructed verbally rather than physically and high levels of reward are administered in the initial stages, gradually being decreased over time. As the child's competence increases the difficulty level is increased along such variables as size of ball, distance from thrower and velocity of the throw. The parent will normally retreat to an earlier step if the child starts to fail so that the success rate is held high while maintaining challenge. Now in psychological jargon we are talking about shaping and fading, varying schedules of reinforcement, proximal zones and behavioural chaining. The psychologist is likely to have a good technical understanding of what is occurring and may be a highly successful teacher. However, they will not match a committed and skilful parent because they cannot match the amount of time available and another essential ingredient – love of the child and an earnest desire for the child to do better.

So what do we know about how to teach well? This is too wide a topic to be covered here as we would need to start with Socrates and work our way forward. There is of course a huge literature on teaching but I want to take a risk and put forward what to me seem the 5 key aspects that make teaching effective. This comes from reviews of the educational literature stretching back many decades in particular, aimed at trying to look at everything from environmental design to gender to class size to teaching strategies. The 5 points are²

- *The amount of time...* Clearly if you spend a lot of time on teaching you will do better than only spending a little time.
- *Actively engaged...* We can all recall times in our school career where we were present but not engaged and the result was that little learning occurred. However, when we were actively engaged in learning the material, it was more likely to be both enjoyed and to remain in our memory. A subset of this point is the speed of learning. If the pace of learning is high it is much more likely that the child will remain actively engaged whereas a slow pace is likely to result in attention drift and engagement being lost. In much of the work that we do we are after a response from students every 2-5 seconds. Of course this is not appropriate in all situations, but it is a common error to teach too slowly – and so get slow learning!

² I am indebted to Darrell Wills from WA who first led me to some reviews that synthesised these issues that were supported in later studies.

- *Material precisely matched to the student's level...* This is a central issue. If material is too hard then failure starts to creep in and avoidance follows. On the other hand, too slow can lead to boredom and a similar disengagement from the teaching situation. To get precise matching it means that we need to carefully assess the student's *skills (NOT IQ!)*. If we don't know the student's current level then matching of material will be by guesswork, which is highly likely to produce bad matching to the student. It also means that in a classroom situation, teaching to the middle of the class is likely to miss a significant proportion of the children (around 30%) due to the material being either too hard or too easy. Children with developmental delay highlight this issue but it is much broader than specific learning labels.
- *That is reinforcing...* This is an obvious point but often overlooked. Whereas adults expect to be paid for work or at the very least be positively acknowledged for it, sometimes we assume that students should learn as a duty. The reality is that unless the student finds the learning rewarding due to its inherent interest or through some external reward, then learning will be slow at best. Particularly for students with a history of failure, self-motivation is likely to be weak and there may be a tendency to avoid all learning or testing situations. Learning is not likely to occur in such situations without some external reinforcement in the early stages.
- *Relevant to the student's world.* If the material is unlikely to be useful or practiced by the student then it is unlikely that it will be retained for long periods. This means that the selection of material is quite important as we often spend large amounts of time teaching things that are not attached to the student's world and then insist on teaching them repeatedly as the student does not seem to be learning. For example, teaching a student the difference between circles triangles and squares is likely to have very limited utility for him or her but have a high probability of turning the student off and even leading to behaviour issues. Of course, this is often a judgement call as material may be essential for a student but its importance not immediately apparent to him or her. In such cases, careful communication of the tasks and good reinforcement are likely to be needed.

So let's look at ways that parents and other concerned individuals can make a difference to people with disability labels all through their life.

Amount of time. A child is normally awake about 100 hours per week and an adult for longer. In that time a huge number of tasks are transacted which can be either learning opportunities or missed learning opportunities. If a decision can be made to select specific activities and set a developmental goal, then just in the normal course of the day's interactions the total teaching could easily be increased by a factor of 5 or 10. For example, appropriate goals could be set in the bathroom, bedroom, kitchen, chores, homework, sport or work, to be transacted as a normal part of daily activity. For specific areas, we have worked with dozens of families to teach their children to read with the initial time cost being about 15-20 minutes per day (easier than it sounds in the long

run). Initially this decision on making time just needs the decision to become more organised, but teaching won't be effective unless the other aspects are also considered.

Actively engaged. The key way to get active engagement is to work on an area of interest to the student. Making learning fun; including physical activity as part of the learning; using valued peers or mentors in the teaching; not allowing learning to go on so long that fatigue sets in; finishing on a positive note while the student is still keen and many other well known strategies can be employed. Two of the most powerful - matching the learning to the student's level and making it reinforcing - are covered below.

Matching material to the level of the student. This is the most complex part of the learning process and it requires considerable knowledge of the student and the task. To take the task first, we need to analyse the task to determine its component parts and the correct order of teaching. For example, if I asked you to tell me how to put my sock on and I followed your instructions exactly, it is highly unlikely that I would succeed in putting my sock on. That is, it needs to be set up (heel down, thumbs inside and top of sock bunched up); then put over toe and the sides gradually released (too hard or too soft a grasp and the task will fail); pull down to bring over heel and then keep pulling and releasing until no more sock is left. And that's just something we have done every day for years and so know it intimately! What is the likelihood of being able to task analyse a skill such as reading or mathematics? In fact, it is not so hard as much of the work has been done in many areas such as self-help and academic skills. However, there will still be many cases where we will need to think the task through to get as precise a match to the student's level as possible. The second aspect of matching, knowing the student's level, requires careful and regular assessment. This is not a major or formal assessment in most cases – it is just regularly checking to ensure that the success rate is high (say, 80% or better) and the student is being challenged appropriately.

Is Reinforcing. When teaching teachers I used to give them a rule: for every criticism you make, you need to make 4 positive statements to correct. It was amazing to see how quickly the teacher students gave up critique and focused on being positive, and in almost all cases the students would respond positively. When working with people who have experienced high levels of failure and rejection, motivation is likely to be low. This will be particularly the case with adults who may have withdrawn from learning altogether so there will be a very high need to accentuate the positive and build up a positive and rewarding learning environment. Sometimes this process can be slow as parents and their children may have built up patterns of responding to each other that are counterproductive. In such cases it may be necessary for someone outside to start the teaching process to get a positive pattern established. In some cases food or other tangible reward may be necessary to start the process, but the aim will always be to bring the reward back to the rewards normally experienced in the natural environment.

Relevant to their world. In many ways this comes down to having a 'big picture' vision as well as an intimate knowledge of the student. If we can link learning into a person's passions and if skills have daily relevance, learning is much more likely to be successful. If we have a vision for a person as enjoying an ordinary life, then we can see what skills are necessary for this to occur and structure teaching appropriately. For example, if the student is included in a mainstream classroom, then learning is much more likely to be successful if the student is accessing the *same* curriculum material as his or her peers; the challenge level is matched to the student's current skill levels; if peers are used as tutors or supporters; the student has valued roles in the classroom and the environment is rewarding of success for all students. In comparison, pulling a student out for special classes is likely to decrease engagement, be punishing rather than reinforcing and be directly contrary to the student's world from his or her perspective. The assumption that these disadvantages will be outweighed by better matching of the task to the student (in segregated education) is not borne out by research. It would be much better to do better matching in the regular classroom.

What does this mean at the different points of life?

The preschool years

It is obvious from the work on early intervention that the more that we can do in these early years the better. Strategies such as waiting for the child to develop or 'grow out of it' are almost certainly going to be ineffective and may actually be harmful. For example letting an undesirable behaviour continue in the hope that the child will grow out of it is likely to produce a larger problem for the future. One of the most powerful strategies that we have found is the teaching of reading as early as possible. The skill is to assess what skills the child has and teach the next possible one in the sequence. This may be as basic as teaching the child to smile on approach of an adult, which could have large social impacts for a child likely to be ignored because of lack of response.

The primary school years.

From the research, the most powerful developmental intervention possible here is to have the child attend the local school in a mainstream class. The child will learn more academically and socially than in a segregated environment and will be better prepared for an ordinary life in the mainstream. Outside of this however, school is a time when parents often leave education to the school and take a step back from their primary role as teacher of their children. This does not mean that parents need to maintain the same level of teaching of their son or daughter as during the preschool years, although any teaching will continue to have long-term benefits. However, a key component of the amount of skills learned and maintained is expectations. As children grow up our expectations normally increase. Where a child has a disability, my experience is that often we pull back expectations in the school years when higher expectations might lead to easier adult transitions.

The high school years:

The research also says that high school children are better included in mainstream education with their regular school peers. Unfortunately Australia is generally behind in high school inclusion although some states are making considerable gains and wonderful outcomes for all children in the schools are being reported. However, for many families there is strong pressure to segregate the child and if the regular school is unresponsive to the issue, children with disabilities can be bullied and isolated. It is not surprising that in such a situation parents will choose to segregate a child rather than have continual rejection and hurt. This segregation is likely to reduce the number of relationships with regular school children and result in fewer opportunities to learn the appropriate skills to interact socially in a teenage culture. This means that the more opportunities that can be made available for the student to interact with similar aged peers the better. This can be done through sports teams, clubs or community groups such as scouts. This will not be easy in many cases, but relationships made here can have wide impacts and keep social skills that might otherwise be lost. The points made for primary school students to maintain high expectations for normal levels of personal responsibility and learn friendship skills can also be made here.

Adult learning

When we look at many of the options made available to adults with disability there is an implicit assumption that learning has either ceased or will occur in micro steps. Post School Activities programs often resemble community visiting schemes with little or no developmental component. If we ask where will these programs lead to in 10 years the answer is normally 'not very far'. Sheltered work is often mind-numbing and repetitive, surrounded by low expectations.

The dream or vision

The first point to consider in adult learning, and indeed in learning at any age, is what is the vision, what is the dream? For many families, just getting through day by day can seem all consuming, but if we can spend some time on dreaming a little, then things can change in the long run. In many cases the person themselves may have a dream, often related to the life outcomes for their siblings that they would like to emulate. It is very easy to crush that dream, but in fact that can be the cruellest thing possible to do as it closes down what might become realities if we can go with a dream. To take what might seem a ridiculous example, what if the person with a significant intellectual disability says they would like to go to university? It is so easy to say this is unrealistic or to tell the person to stop being silly. However, if we consider what we get out of university we might list such things as:

- a degree
- lifelong relationships
- social opportunities
- knowledge
- immersion in the university culture (drinking, parties ...)

- housemates
- lifelong networks
- ...

Now if we look at this list, the only thing not realistically achievable is the degree. If we structured the situation well, all of the other things might occur to some extent at least which could have life changing outcomes. The question then becomes “How can we do it?” which has resulted in several examples around the world for nearly 2 decades. The key point is to not take on the negative expectations that have been ground into us on a continual basis by many services, professionals and the society generally.

If our son with an intellectual disability says he wants to be a brain surgeon, what is the correct answer? The correct answer is “Okay, let’s go for it! So first we will need to ...” and so start the journey towards the dream. Over time, in the same way as for all of us, dreams become readjusted by reality but the outcome is likely to be involvement in an area of interest and major skill and relationship gains.

Valued Roles

One of the most helpful means to envision a better life is to think in terms of valued roles. Valued roles are like the passport to an ordinary life. They are the means that we gain skills, become known, respected and connected with each other. If we think through our lives, we move daily through a succession of valued roles such as parent, sibling, food provider, home owner, driver, colleague, friend, club member and citizen. If any one of these roles is threatened (losing one’s job or licence for example), the impact is deep and very discomfoting, giving us an idea of how powerful these roles are to us.

However if we look at the lives of many people who carry a label, their range of valued roles is severely limited or even non-existent apart from the family roles. The good side is that there are **thousands** of valued roles available. Even just looking at work roles, the number of jobs possible would fill books, so there must be some potential to carve out a realistic work role for many people with disability. There are also many valued roles available outside of employment, both in work (i.e. is in contributing for no money) and in community activities such as sport or club membership.

In considering which valued roles to work towards, the interest and dreams of the person will be the first point of consideration. People who have previously shown little motivation to try anything can become enlivened if someone takes their dream seriously. Another consideration is the likelihood of the role opening up other possible roles (e.g. friend, colleague, organiser); the probability of it leading to real relationships, and the number of skills required to hold down the role.

Thinking developmentally

If we look at where a person lies on the continuum of being able to hold down a valued role such as a real job, the gap can seem so large that it appears futile and possibly damaging to even embark on the process of building the skills necessary. However, some alternative ways of accessing the role with little danger to reputation but good likelihood of gaining access to skills and other roles might be:

- partner to someone fulfilling the role
- part of a group role
- mentored into the role
- short time in the role
- fulfilling parts of the role
- joining achievable parts of several roles together to develop a new role

Taking this thinking a little further, why not put the person straight into a powerful role with a partner, and set a goal of, say, 15 years for the person to be able to do most or all of the role. For example, putting a person into the role of manager where initially a partner is doing effectively all of the role. This is effectively what happens to us when we first move into a senior role. Initially, we are heavily supported by others but over time our capacity and confidence increase. The difference is that the lead time in this case is extended considerably, but the job is still being done. This is after all what happens if a king or queen dies when their son is very young. The son takes on the role but it is actually performed by someone designated for the role. Over the years however, the son gradually takes on the whole role. Using this way of thinking we can open up a range of possibilities such as people running their own business or filling a senior role in a business or club.

We can also think of development as being multifaceted. Not only does the person develop skills, we get better at the supporting role, the community gets better at acceptance and the expectations of all increases.

Summary

There is a saying that is highly pertinent to this area:

Question: "How do you eat an elephant?"

Answer: "One bite at a time!"

The message is that if we have high expectations, a clear vision and a consistency of approach, huge gains are possible and what seemed like nonsense can become a reality. Development does not stop for us and we would reject the idea of having reached our potential with only a plateau or decline before us. Why should we accept it for people with decades of real possibilities before them?

So the vision is:

- Explore dreams with the person and DO ask “What do you want to be when you grown up?”
- Set goals and steps on the way.
- Keep expectations high. It is better to have a high expectation and fail to meet it than to set and meet a low expectation.
- Visualise valued roles and try to put the person into such roles with support, withdrawing the support as the person’s skills increase.
- Believe in yourself as you are a great teacher – and can be better.

Include Pty Ltd

www.include.com.au

bobjackson@include.com.au

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