Best Practices For Providing Transition Services For Children With Down's Syndrome: Potential Applications for Saudi Arabia

by Randah Saleh Al-Ojaimi University of Akron

Abstract:

In Saudi Arabia, students with intellectual disabilities are typically educated in segregated environments and live their lives in isolation from mainstream society. This lifelong isolation severely limits their prospects for achieving positive quality of life outcomes such as steady employment or independent living. Fifty years ago, this experience was also quite typical of this population in other countries, such as the United States. However, in the intervening years, greater efforts have been made to improve the lot of the intellectually disabled, and much has been learned about what works and what does not.

A major transition in anyone's life is the one from school to adulthood. This transition can be even more daunting for persons with intellectual disabilities. For this reason, transition services are an important feature of special education in the United States and many European countries.

This paper provides an overview of currently accepted best practices in transition planning for students with Down Syndrome. Learning in an inclusive environment provides an important foundation upon which to build transition services. With this foundation in place, four elements of a transition plan were found to contribute strongly to the successful transition to adulthood for a student with Down Syndrome. First is the extent to which the student's ability to make (or at least have a voice in) the decisions that affect him/her (self-determination). Second is the extent to which the student is involved in shaping his/her own IEP. Third, the transition plan requires a high level of collaboration among the participating parties (student, family, teachers, community members, agencies, etc.). Finally, it was found that students can benefit greatly from participating in community based activities while in school as preparation for becoming fully participating members of that community.

ملخص الدراسه :

عنوان البحث : أفضل الخدمات الانتقاليه لمتلازمه داون لتطبيقها في المملكه العربيه السعوديه

يعاني الطلبه والطالبات من ذوي الاعاقه الذهنيه في المجتمع مثل مجتمع المملكه العربية السعودية من عمليه فصلهم عن نظر ائهم الاصحاء في التعليم وايضا عن الحياه الطبيعية في المجتمع. هذا الفصل يقلص من امكانيات ذوي الاحتياجات الخاصه وخصوصا الذهنيه منها من الانخر اط في المجتمع سواء عن طريق العمل او حتي العيش المستقل ويجعلهم عاله علي ذويهم. في الخمسين سنه الماضيه كان هذا الحال أيضا مماثل في كثير من الدول ومنا الولايات المتحده الامريكيه،لكن، في العصر الحالي الكثير من الجهود بذلت لتخطي مثل هذه العقبات التي تواجه ذوي الاحتياجات الخاصه وخصوصا الذهنية منها وتم التعرف علي الطرق التي تفيد في بناء مجتمع متكامل وايضا كيفيه مواجهه العقبات .

تعتبر المرحله الانتقاليه من الطفوله إلى المراهقه هي اصعب المراحل الانتقاليه لاصحاب الإعاقات الذهنيه ومن هذا المنطلق تعتبر الخطط الموضوعه والدر اسات المقامه أهم سبل المساعده في تسهيل وتسيير مثل هذه الصعوبات سواء بالولايات المتحده الامريكية أو بعض الدول الأوروبيه عن طريق استخدام أسلوب تدريسي متطور يطلق عليه طرق التعليم الخاص بذوي الاحتياجات الخاصه

هذه الدراسة تقدم لمحة عامة عن افضل الممارسات المقبولية حاليا والعمول بها في الولايات المتحده الامريكية لتسهيل العملية الانتقالية والدمج بين ذوي الاحتياجات الخاصة وخصوصا مرضي متلازمة داون ونظرائهم الاصحاء.

اعتمدت الدراسه علي حصر اربعه عناصر أساسية تساهم بشكل رئيسي في بناء خطه الدمج لمرضي متلازمه داون في المجتمع .

أول العناصر هو مدى قدرة الطالب على جعل (أو على الأقل يكون لها صوت في) القرارات التي تؤثر عليه / عليها (تقرير المصير).

والثاني: هو مدى قدرة الطالب تشارك في تشكيل الخطه التربويه الفرديه الخاصه به. ثالثا الخطه الانتقاليه أو خطه الدمج تستلزم مقدارا عاليا من التعاون بين المشاركين سواء من مدرسين، الاسرة، الطلاب ، أفراد المجتمع، الهيئات المتخصصة، وكل من يستطيع تقديم يد المساعده . العنصر الأخير وضع بناء علي در اسات استنتجت أن ذوي الاحتياجات الخاصه وخصوصا مرضى متلازمه داون يمكنهم الاستفادة من المشاركه في الانشطه الاجتماعيه اثناء تواجودهم في المدارس مثل العمل التعاوني حيث ان هذه الانشطه تساهم في شكل فعال لإعدادهم ليكونوا أعضاء فاعلين في المجتمع مستقبل.

Introduction

Down's Syndrome (DS), also known as Trisomy 21, is a genetic disorder resulting from having an extra chromosome, that commonly results in mental and physical developmental delays and is characterized by easily recognizable facial features. DS is the most common cause of intellectual disabilities (ID), although the severity of these disabilities varies (Pace, 2001; Weijerman & Winter, 2010). It is estimated that 1 in 691 live births in the United States results in DS (Parker, Mai, Canfield, Rickard, Wang, Meyer, Anderson, Mason, Collins, Kirby & Correa, 2010); the frequency of DS in the Kingdom of Saudi Arabia (KSA) appears to be significantly greater, with one study placing its incidence at 1 in every 554 births (Niazi, Al-Mazyad, Al-Husain, live Al-Mofada, Al-Zamil, Khashoggi & Al-Eissa, 1995). It has been observed that genetic disorders are generally more common in the Arab world than elsewhere, possibly owing to higher rates of consanguinity (El Mouzan, Al Salloum, Herbish, Qurachi & Al Omar, 2008, p. 169). While DS may be more common in Saudi Arabia, the children afflicted with DS there face a bleaker future than they do in the United States because they face social ostracism and because they do not have access to the same range of services as their counterparts in the United States (Al-Jadid, 2013). Overall, special education services are much more limited in Saudi Arabia and social attitudes are much less accepting of people with intellectual disabilities (Alnahdi, 2013; Mansour, 2009). In particular, special education students in KSA are much less likely to enjoy the benefits of working alongside their peers in regular education classes. Rather, they are likely to be housed in a separate building or at least in a different part of the main school building, so that their exposure to their non-disabled peers (if any) is generally limited to periods such as recess and lunch.

One way in which children with DS in the United States (and other countries such as the UK, Sweden and Australia) have an advantage over those in KSA is the preparation they get for life after their school years are over. The 2004 Individuals with Disabilities Education Act (IDEA), among many other things, requires that special education students receive preparation (i.e. transition services) for the unique challenges that will face them after their school years are over. These students' IEPs must be oriented toward planning for the years after formal public schooling ends, including areas such as employment, independent living, and community participation (Wrightslaw, 2006). In Saudi Arabia, there is legislation on the books that makes similar provisions, but it has yet to be fully implemented (Alquraini, 2010).

In the KSA, there are also laws that have been approved, but the implementation has led to quite a different experience. For example, while the Provision Code for Persons with Disabilities (2000) calls for a free appropriate public education to be offered to all students, students with disabilities are generally segregated, away from the general student population and receive little in the way if transition services (Alquraini, 2010). As a result, they are generally poorly equipped for independent living or for pursuing their interests once they leave the school setting.

The transition to life after school presents a number of challenges for a youth with Down's Syndrome. While the exact combination of these challenges (and their severity) varies from individual to individual, they are generally shared by children with other types of intellectual disabilities. Because the intellectual disabilities observed in persons with Down Syndrome span such a range and lack specificity (Weijerman & Winter, 2010), this author will treat the intellectual disabilities associated with Down Syndrome as interchangeable with the broader, more general category of mild to moderate intellectual disabilities, unless there is a particular reason to single out the Down Syndrome subset of the broader population of persons with mild to moderate intellectual disabilities.

These challenges fall under two broad categories: employment and independent living. The category of employment includes issues such as identifying an individual's abilities and interests, how to find and secure an appropriate job, understanding the range of job possibilities available, workplace expectations (conduct, dress codes, punctuality), identifying the most appropriate course of study, and identifying what academic or workplace supports (if any) are needed by the individual. The other broad category, independent living, includes social skills, living skills, how to identify and access community resources, and how to overcome social attitudes and prejudices. An additional issue for students with Down's Syndrome is the physical problems that characterize this condition and the ways to manage them.

In examining successful approaches to providing transition services for children with Down's Syndrome, this review includes existing literature on providing services to intellectually disabled children (particularly children with Down's Syndrome) and determine what are the currently accepted best practices for ensuring that this major life transition leads to positive outcomes in adulthood. Just as "it takes a village to raise a child," it also takes the combined efforts of a number of different people playing different roles to make the transition process yield positive results. These stakeholders include individuals involved in the child's school (i.e. where the child is transitioning *from*) -special education teachers, family members, school administrators, regular education teachers (particularly those who have inclusive classrooms) - and in the broader community (where the child is transitioning *into*) – agencies that provide supportive services, potential employers and post secondary institutions. In Saudi Arabia, such connections have been severely neglected; a study by the Japanese government found that more "attention has been placed on person with disabilities health care services rather than education and training, and there is very little attention given to helping persons with disabilities gain employment (Japan International Cooperation Agency Planning and Evaluation Department, 2002). Almost 10 years later, Alquraini (2010) found the situation essentially unchanged. In conducting this literature review, it is hoped to assemble a set of principles and best practices that may be applicable to the field of special education in Saudi Arabia.

As a Special Education teacher in Saudi Arabia, this author hopes to promote a greater understanding of approaches to educating special needs children that are successful in other countries. It is hoped that, armed with this greater understanding, Special Education teachers in Saudi Arabia will be able to make a meaningful contribution toward improving the lot of special needs children (and the special needs adults that they eventually become) in Saudi Arabia. Although the children that this author teaches represent a wide variety of disabilities, the focus selected is on those with Down's Syndrome both because it is relatively common, but also because those who have DS are physically marked by it and are thus inevitably subject to the widely held prejudices against the disabled that exist throughout Saudi society. On the other hand, in this author's experience, students with DS have generally had characteristics (positive attitudes, outgoing personalities) that make them more likely than other categories of disabled student to achieve a good quality of life as adults.

Literature Review

The reforms in US schools that have resulted in steadily increasing rates of inclusion over the past four decades have been based on the principle that <u>all</u> children have the right to the best possible education in the least restrictive environment. Proponents argue that students with disabilities should not be deprived of the opportunity for a quality education simply because they have disabilities. Furthermore, they argue that segregating special needs children in their own classes deprives the regular students of valuable social experiences. Thus, the segregation

مجلة البحث العلمي في التربية

model disadvantages both sets of students (Gerrard, 1994). In addition, inclusion proponents argue that teachers in segregated programs have lower expectations and that students in segregated programs generally do not have the benefit of individualized programs. As a result, students in segregated programs tend to stay in segregated programs, a completely unnecessary state of affairs because most regular education teachers are willing and able to teach special needs students (Southwest Educational Development Laboratory, 1995).

In addition to this ethical/moral/philosophical argument, inclusion proponents note that there are a number of positive outcomes associated with inclusion and that the misgivings expressed by inclusion opponents are often overstated. Villa and Thousand (2000) point out that the practical objections to greater inclusiveness may not have much merit, citing studies that indicate that special education students who are placed in mainstream classes show improved levels of achievement over their segregated peers. Baker, Wang & Walberg (1994) reviewed three meta-analyses, and concluded that inclusion yields better academic and social outcomes for students with disabilities than do segregated learning environments. Hunt, Farron-Davis, Beckstead, Curtis & Goetz (1994) studied pairs of disabled students in 16 programs with different levels of inclusiveness, found that disabled students who were educated in more inclusive environments demonstrated higher levels of engaged behavior. Wagner, Newman, Cameto, Levine, & Garza (2006) examined the results of the National Longitudinal Transition Study-2 and found that the increased time a spent with non-disabled peers during one's school years was positively associated with higher levels of employment and independent living after high school.

On the other hand, research indicates that disabled students' mainstream peers benefit from inclusive classes, not just in terms of learning and but also in terms of social and emotional growth. Cole, Waldron, Majd & Hasazi (2004) studied six Indiana school districts and found that students without disabilities who learned in in inclusive environments made greater academic progress in mathematics and reading than those who did not have exposure to disabled peers. Katz and Mirenda's (2002a and 2002b) review of the existing literature concludes that both disabled and non-disabled students stand to benefit, both in the short and longer terms, from sharing an inclusive learning environment with each other. Furthermore, Baer, Daviso, Flexer, Queen & Meindl, (2011) found that being an inclusive environment was a more significant predictor of whether intellectually disabled students went on to pursue

مجلة البحث العلمي في التربية

post-secondary education than were other factors, such as the child's participation in career and technical education and work-study programs. In this study, approximately 4,000 students in the United States with mental retardation were interviewed one year after high school graduation.

In Saudi Arabia, the school environment for children with Down Syndrome is more likely to be segregated than inclusive. The Saudi Government, which plays a much stronger role in the field of education than does the American government, recently announced that it would pay the full cost for the "treatment and rehabilitation" of children with Down Syndrome (Al-Qabousi, 2014). While generous, this gesture reveals a lack of understanding on the part of the issues faced by persons with DS as they grow older. In addition, the model for educating children with Down Syndrome in Saudi Arabia, the Saut School in Riyadh, proposes a completely segregated environment for these children.

By participating in an inclusive school environment, a child gains a foundation for subsequent development. Thus, the relative success of any transition process will depend heavily on the type of environment from which a child is transitioning. Nevertheless, not all inclusive school environments are equal. A number of factors distinguish inclusive school environments from one another, with potential implications for the ease of a child's transition into adulthood.

Transition Services

When high school seniors complete their schooling, they leave an environment (school) that they have become familiar with over many years and exchange it for one that is much less familiar to them: the world of work and independent living. This transition can present an enormous challenge for a mainstream student, but is especially challenging for someone with intellectual disabilities, especially if that person has had limited experience with the "real world." Transition services seek to bridge this gap, familiarizing the student with this new terrain and what it will take to navigate in it (McDonnell & Hardman, 2010). Elements of a transition regime that can have a strong influence on the post transition outcomes include those that fit under four broad categories that will be considered in this review of existing literature: self determination, individual education collaboration (among students, family members, community plans. resources, educational staff), and community-based experiences.

One practice in the US that could be useful in Saudi Arabia is the use of transition linkage coordinators (TLCs), designated persons who work with all concerned parties - the students, their families, schools (teachers

مجلة البحث العلمي في التربية

and administrators), employers and community based agencies – to ensure that the students and their families understand the options available to them and to ensure that they can effectively access any appropriate services in planning and executing the child's transition to adulthood (Noonan, Morningstar & Erickson, 2008). In Saudi Arabia, even specialized schools and private schools that have more resources than public schools do not have transition coordinators.

McWilliam (2006) recommends strong parental/family involvement in planning and guiding the transition process, while noting the importance of coordination with community-based agencies. However, in Saudi Arabia, children with Down Syndrome are generally not only segregated from their student peers, but also from society at large (Alnahdi, 2013). As a result, these children do not reap the potential benefits of exposure to nondisabled peers and do not gain an understanding of how to navigate their community, making it significantly less likely that they will be able to achieve a successful transition to independent living or steady, satisfying employment.

Self-determination

A growing body of research indicates that the degree to which persons with intellectual disabilities are able to make the decisions that affect the course of their lives has a direct bearing on the quality of life that they enjoy. Wehrmeyer and Schwartz (1997) studied a group of 80 students with cognitive or learning disabilities, beginning their last year in high school; they assessed them for measures of self-determination. They then charted the students' progress over the next year and found that those individuals with mental retardation or learning disabilities who were more highly selfdetermined experienced greater positive outcomes as adults (e.g. higher rates of employment, higher levels of income). The generalizability of such a study is limited, however, by the heterogeneity of the group of students in the study – they represented a range of communities and had a variety of different impairments. Wehrmeyer and Palmer (2003) conducted a more robust follow up study, in which they monitored the progress of 94 students with cognitive disabilities from their last year in high school through the third year after their departure from school. They found that those individuals who demonstrated higher levels of self determination were much more likely to live independently, and to obtain workplace benefits, such as vacation, sick leave, and health insurance. Benz, Lindstrom & Yovanoff (2000) found that adolescents with disabilities (including intellectual and developmental disabilities) and who completed transition

مجلة البحث العلمي في التربية

goals that they themselves had identified were significantly more likely to graduate a to achieve positive employment outcomes. Wehrmeyer and Schwartz (1998) studied a group of 50 adults with mental retardation and found that their levels of satisfaction had a strong correlation to their levels of self-determination. Lachapelle, Wehmeyer, Haelewyck, Courbois, Keith, Schalock, Verdugo & Walsh, (2005) conducted a similar study with a larger, more international population. They studied 182 adults with intellectual disabilities (ID) living in four countries (Canada, United States, Belgium and France) and found a direct correlation between selfdetermination and quality of life (QOL). Nota, Ferrari, Soresi & Wehmeyer (2007) studied 141 individuals with intellectual disabilities in Italy and the relationships among factors such as IQ, self-determination, age, social abilities, and quality of life. Like the previous studies, they found self-determination to be linked to quality of life.

While these studies have addressed the relationship of selfdetermination to adult outcomes in persons with intellectual disabilities, an admittedly broad category, the relevance of self-determination to persons with Down's Syndrome is underscored by the leading roles of the National Down Syndrome Society and the National Down Syndrome Congress, the two main national advocacy organizations in the United States, in both the founding, as well as the ongoing activities of the Collaboration to Promote Self Determination (CPSD), a coalition of 22 organizations that promotes the reform of disability laws, with a particular emphasis on increasing self-determination among the disabled (Collaboration to Promote Self Determination, n.d.). The CPSD orients its advocacy activities around the principles that (1) disabled students should have access to an inclusive educational environment, (2) the disabled should be supported in a way that enables them to live as independently as possible, (3) the disabled should have access to employment that provides a sustainable income, and (4) that the disabled should be afforded opportunities for economic empowerment.

Having established the connection between self-determination and positive adult outcomes among intellectually disabled persons¹, the question that raises itself is that of how to foster self-determination within students. One model of instruction that explicitly seeks to accomplish this is the Self Determined Learning Model of Instruction (SDLMI) (Wehmeyer, Agran, Palmer, Mithaug & Blanchard, 1998; Wehrmeyer, Palmer, Agran, Mithaug & Martin, 2000). SDLMI consists of three phases in which students are encouraged to ask themselves specific questions relating to particular themes. In the first phase, students set goals for themselves – these may be behavioral, social, or academic in nature. In the second phase, students craft a plan for achieving these goals; again, the student-centered nature of the process is emphasized. In the third phase, students reflect on whether they have achieved their goals and whether to consider altering either their strategies or their goals (Palmer, Wehmeyer, Gipson & Agran, 2004).

A number of studies have indicated that SDLMI is an effective way of promoting self determination in students. Agran & Wehmeyer (2000) found that SDLMI was effective in making the general curriculum accessible to students with intellectual disabilities. Lee, Wehmeyer, Palmer, Soukup & Little (2008) found both that promoting self determination increased disabled students' access to the general curriculum and that SDLMI was effective in increasing students' self-determination; however, the sample size for this study was relatively small. It is worth noting that Wehrmeyer participated in all of these studies (Wehrmeyer, Palmer, Agran, Mithaug & Martin, 2000; Agran & Wehmeyer, 2002; Lee, Wehmeyer, Palmer, Soukup & Little, 2008), and this researcher did not find any studies evaluating SDLMI in which Wehrmeyer was not one of the principal researchers.

Individual Education Plans (IEPs)

Another way that self determination can be promoted is by means of a self directed IEP. The involvement of the student with disabilities in the process of planning his/her future is a practical exercise that can help to

¹ In the literature that examines the relationship between self-determination and adult outcomes among the intellectually disabled, persons who have intellectual disabilities as a result of Down Syndrome tend not to be treated separately from those with intellectual disabilities that results from other causes. Consequently, those with Down Syndrome are treated as an undifferentiated subgroup of the intellectually disabled.

727

build confidence and assertiveness (Gartin & Murdick, 2005). The principle that students with disabilities should have a voice in shaping their IEPs was incorporated in the IDEA requirements for IEPs of students with disabilities. In 2001, the University of North Carolina at Charlotte completed work on the Self-Determination Synthesis Project (SDSP), whose purpose was to examine the existing knowledge base regarding self determination of children with disabilities and to establish a set of best practices for promoting self determination with this population (University of North Carolina at Charlotte, 2001). Wood, Karvonen, Test, Browder & Algozzine (2003) argued that while it is important to have a student take a leadership role in designing his/her own IEP (and thereby exercising a measure of self-determination), it is also important that the IEP's goals and objectives specifically target self determination and transition plans and concepts of self determination. In particular, they argue for employing the components of self-determination, as originally identified by Wehmeyer (1998), as guiding principles around which to organize an IEP. These components include goal making skills, self-regulation skills, self awareness and self advocacy.

Collaboration Leading to Independence

The tacit assumption of the idea that "it takes a village to raise a child" is that the "villagers" who are participating in the project of raising the child would function most effectively if they coordinated their efforts rather than each of them operating independently of the others. In other words, it would behoove these parties to collaborate with one another. The logic of this argument can be extended to the transition process and the various school parties (family members. administrators, teachers. community members, community agencies, etc.) who participate in the different stages of a child's transition from school to adulthood. While the value of this approach is recognized as a best practice (Parent Advocacy Coalition for Educational Rights Center, n.d.), it is not always applied, whether for lack of resources, parochial political decision making, or some other reason. Benz, Lindstrom & Latta (1999), noting the importance of collaboration among stakeholders, highlighted the model of Oregon's Youth Transition Progam (OYTP), which strongly emphasizes interagency collaboration in transition planning and implementation. In endorsing the OYTP as one of its 10 best practices, the European Association of Service Providers for Persons with Disabilities (EASPD) noted that 80% of OYTP participants "are engaged in employment or post-secondary training upon completion of the program" (OYTP, n.d.). Under this program, YTP staff facilitate the coordination of individualized student/school plans (which

emphasize goal setting and self determination) with community agencies, and teach vocational, independent living, and job readiness skills to students. The program also provides follow up support for the year after the conclusion of the program to ensure that positive outcomes are maintained (European Association of Service Providers for Persons with Disabilities, 2013). As in most other documents in this literature review that have focused on persons with disabilities, the relative prevalence of persons with Down Syndrome in the overall population being discussed is not made clear.

The National Down Syndrome Society has identified three categories of employment that are available to persons with DS. Competitive employment refers to jobs that offer either no supports or very limited job supports, ² while supported employment offers more extensive and longer term access to such supports. Finally, sheltered employment offers work in a segregated setting and the pay is tied to productivity, so the wages tend to be significantly lower than in competitive or supported settings (National Down Syndrome Society, n.d.).

Students with Down Syndrome must be prepared for the range of employment possibilities that is available to them when they complete school. This entails gaining an understanding not only of what possibilities exist in their community, but also what is necessary to take advantage of those opportunities (e.g. how to get and keep a job that they will be happy and successful at, what workplace expectations and rules are), as well as the range of supports that are available to them and how to access these. This process is facilitated when relationships are established between schools and agencies tasked with vocational rehabilitation (Edmonson & Cain, 2002; Oertle and Trach, 2007). Benz et al (2000) found, in their study of 709 participants in Oregon's YTP program, that students who participated in some form of paid employment during their last two years of high school were much more likely to enjoy positive employment outcomes after the conclusion of their school years. The results are somewhat unsurprising, as one might expect individuals with greater workplace experience to have a distinct advantage over those who do not. Nevertheless, the question that then becomes most pressing is how to get

۶ £ ۷

² Job supports include having a Job Coach/Employment Specialist accompany the client to work and help them to get acclimated to the job. In competitive employment, this type of support would only be available for a short time, if at all; in a supported environment, the Job Caoch would be available for a longer term period of time, even indefinitely.

students with Down Syndrome this valuable experience before they complete their school years.

Renzaglia and Hutchins (1988) propose a systematic program for vocational training and preparation; they recommend that vocational training begin by age 13, if not earlier, to allow for the extra time that may be needed to absorb the necessary information and to develop habits that will lead to successful workplace outcomes. A crucial first step is that a community assessment be carried out. Such an assessment would identify what relevant employment opportunities exist in the local community, what skills are required in those positions. Employers must also be assessed for a number of factors, including their willingness to hire persons with intellectual disabilities and to permit on the job training (and other supports), as well as the working conditions that are on offer (this can include the physical working conditions and the conditions of employment, such as wages, hours and benefits).

Once these assessments have been made, educators must then formulate strategies that put their students in the best position to be able to seize the available opportunities and to succeed one they have secured them. Typically, this step entails a training regime which will equip students with the skills and habits that are needed for specific jobs. Training may take place in in-school settings that are designed to replicate the types of settings that might reasonably be expected to be encountered in a real life work environment. This approach is more effective if the facilities used for vocational training of nondisabled students is available (and especially if they have the opportunity to learn alongside their nondisabled peers). However, Renzaglia and Hutchins point out that it is difficult to effectively simulate the conditions and demands of a real job, and as a result, simulated employment often provides inadequate preparation for a real job.

While employment is a crucial component to life after the end of school, it is certainly not the only one. Independent living, or living with minimal supports, is also a primary goal of any transition plan. As in employment, successful outcomes in this multilayered category depend on a collaborative approach from a number of parties in establishing goals, developing strategies to meet them, and then executing those strategies. Again, because of the natural variability among individuals (i.e. in their preferences, abilities, etc.), there is no one-size-fits-all approach that is suitable for every individual.

مجلة البحث العلمي في التربية

It has been suggested that families play such a key role in preparing students for community living that such preparation should begin in earnest as early as elementary school (Turnbull, Beegle & Stowe, 2001; Dunst, 2002; Wehman, 2006). One approach toward developing students' educational plans that has gained some currency is Person-Family Interdependent Planning (Kim & Turnbull, 2004). According to this perspective, the student and his/her family are the primary decision makers regarding the student's present and future needs, and the family, in serving as the student's "functioning social support unit" during the transition years requires support to effectively carry out this function.

In order to build the student's competence in living independently, a transition plan should seek to build up various skills in a systematic and cumulative manner. In order to ensure that this process unfolds successfully, it is important to continuously reevaluate the student's progress toward acquiring targeted skills, and to adjust goals periodically to incorporate increasingly complex outcomes (Jameson & McDonnell, 2010).

Community-based Experiences

While classroom and school-based instruction have undeniable value in preparing students with Down's Syndrome for life after their school years, there is much to be gained from exposing students to life beyond the confines of the classroom (and the school). It stands to reason that an effective preparation for life in the "real world" should include at least some direct exposure to that environment, rather than providing a purely theoretical or simulated type of preparation. Just as it has been demonstrated that inclusive classrooms benefit both disabled and the nondisabled students, there is mutual benefit to be gained from Down Syndrome students interacting regularly with persons who represent the variety of persons in the general population. Jain, Thomasma & Ragas (2002) note that greater exposure to the broader community from an early age can not only help to reduce the stigma associated with Down Syndrome, but it can promote a wider acceptance of the condition.

Just as nondisabled students benefit from instruction that is connected with real life situations because this type of instruction has inherent relevance to them, disabled students can benefit from communitybased instruction, particularly as this relates to their transition out of school. Dubberly (2012) surveyed 91 students with intellectual disability regarding their experience with community based learning and found very high levels of satisfaction with the approach. In particular, they expressed increased levels of self determination and self efficacy as a result of community based learning.

30.

By participating in real-life work experiences based in their local communities, student with disability can develop skills and learn about the types of work that may be available to them as adults. Experiences that allow individuals to work with supervisors and others, do work tasks, and get accommodations enable students to figure out what types of employment they might want to pursue, to develop interpersonal skills, and to become confident and able to adapt to different situations (Swedeen, Carter, Trainor, Ditchman, & Owens 2009).

Local businesses also benefit from these types of programs because they increase the supply of workers who are ready to join the workforce, and they themselves learn how to create work environments that maximize the productivity of the workers' with disability. Such work experiences can also serve to promote more positive attitudes toward persons with disabilities (Burgstahler, 2001). The practical real world experience that students get from these types of programs opens doors to opportunities that might otherwise not be available to them, such as the possibility of extending school year employment into the summer.

Renzaglia and Hutchins (1988) note that community based employers can serve a range of functions for high schoolers with moderate to severe intellectual disabilities. They can act as training centers, but only if they offer a range of activities (that can lead to the acquisition a range of skills) that are representative of the types of work activities that could reasonably be expected to be encountered at other, similar employers in the community. Placement sites are those that hold the genuine prospect of offering future employment for the students; these sites must be assessed for their potential for providing on the job training and any needed follow up services. Typically, these sites accommodate a smaller number of students who must be matched more specifically to the site based on their skills, interests and other factors. Some sites fulfill both functions, providing both training in specific skills, while grooming individual students for placement once they graduate.

Beyond the goal of developing a broadly applicable quality like self determination, the National Collaborative on Workforce and Disability (NCWD) has identified what it calls The Guideposts for Success (United States Department of Labor, n.d.), the five elements that are crucial to a successful transition to adulthood:

1. School-Based Preparatory Experiences;

- 2. Career Preparation & Work-Based Learning Experiences;
- 3. Youth Development & Leadership;
- 4. Connecting Activities; and
- 5. Family Involvement & Supports

Two states, Maryland and South Carolina, have been particularly enthusiastic about implementing the Guideposts agenda. To date, however, there has not been a rigorous evaluation of these two states' programs (US Department of Labor, n.d.).

Conclusion:

A review of the existing literature relating to successful transition programs yields a number of general conclusions. Perhaps foremost among these (given that the purpose of this exercise was to relate the state of the art in transition programs to potential applicability to Down Syndrome students in Saudi Arabia) is the researcher's finding that there is very little research that focuses specifically on students with Down Syndrome and the transition programs that work best for them. Rather, these students tend to be lumped into the broader category of "students with mild or moderate intellectual disabilities." This is not altogether surprising, as the intellectual disabilities associated with DS are not of a particularly distinctive character. Nevertheless, DS students are a distinct (and distinctive) population, and they merit additional study that might winnow out any differences that may not be immediately evident.

In reviewing the existing literature on successful transition programs for the broader category of intellectually disabled students, some general themes have emerged. First is that an intellectually disabled child can gain a great advantage from learning in an environment where he/she has many opportunities to interact with non-disabled peers and to participate in the regular school curriculum in a supported and supportive atmosphere. For these conditions to be met, a school's staff and administration must buy into the idea that there is value in including disabled students in the regular school program. As leadership figures, they set the tone for the children in the regular student population, modeling behaviors and attitudes that can make it more likely that these children will accept the disabled children in their midst.

Another element of successful transition programs is the extent to which they promote the student's capacity to make the decisions that affect them directly. Higher levels of self determination have been linked to greater quality of life outcomes (levels of employment, income levels, job satisfaction) among intellectually disabled students. One method for promoting self determination among intellectually disabled students, the Self-Determined Learning Model of Instruction (SDLMI), appears to be particularly successful, but the research evaluating this method is also strongly tied to its principal exponent, Michael Wehrmeyer, a fact that invites speculation regarding bias. These doubts could be allayed if other researchers were to undertake their own assessments.

The Individuals with Disabilities Education Act (IDEA) incorporates the idea of self determination in its requirement that disabled students' IEPs take into account the student's preferences, effectively making the student a member of the IEP team rather than simply the object of the IEP planning process. Further, the concept of the IEP as a group project reflects the importance of viewing the transition process as a collaborative effort, involving the student, his/her family, teachers, school administrators, local communities (including employers, service agencies, and others). Where resources are available, it is desirable to have a designated individual charged with ensuring that these disparate parties communicate and collaborate with one another rather than working at cross purposes or duplicating one another's efforts.

While classroom- and school-based learning are the standard models, community-based learning can be an invaluable supplement. By engaging with the community that he/she will eventually enter, the two entities become familiar with each other, naturally easing the potential shock which would be associated with a more abrupt transition. Community-based learning helps all parties (i.e. the students, their families, community members such as potential employers and landlords) grow familiar with one another (thus removing some of the social stigma associated with persons with Down Syndrome, but also enables them to set reasonable expectations for what may be possible or desirable for the student once he/she leaves the school environment. Community based learning also gives the students real world survival skills (their employability, social skills, independent living skills, etc. in a significant way.

مجلة البحث العلمي في التربية

For all the promise that these insights and interventions hold, their applicability to Saudi Arabia is severely limited. Individuals with intellectual disabilities are typically isolated from the remainder of society, starting in their school age years and continuing throughout their lives; this segregation feeds into popularly held prejudices, creating a vicious circle. Over the past 60 years, the United States has found its way out of a similar vicious circle, but the American experience may be of limited value as a model, given the pronounced differences in culture and societal structures.

204

References:

- Agran, M., Blanchard, C., Wehmeyer, M., and Hughes, C. (2002). Increasing the problem-solving skills of students with developmental disabilities participating in general education. *Remedial and Special Education, 23*, 279-288.
- Agran, M. & Wehmeyer, M. (2000). Promoting Transition Goals and Self-Determination Through Student Self-Directed Learning: The Self-Determined Learning Model of Instruction. *Education and Training in Mental Retardation and Developmental Disabilities*, 35 (4), 351-364.
- Al-Jadid, M. (2013). Disability in Saudi Arabia. *Saudi Medical Journal*, 34 (5), 453-460.
- Alnahdi, G.(2013). Transition Services for Students with Mild Intellectual Disability in Saudi Arabia. *Education and Training in Autism and Developmental Disabilities*, 48 (4), 531–544.
- Al-Qabousi, S. (2014). Government to bear cost of treating kids with autism and Down Syndrome. *Saudi Gazette*. Retrieved from <u>http://www.saudigazette.com.sa/index.cfm?method=home.regcon&c</u> <u>ontentid=201</u> 40918218572
- Alquraini, T. (2010). Special Education In Saudi Arabia: Challenges, Perspectives, Future Possibilities. *International Journal of Special Education*, 25 (3), 139-147.
- Baer, R., Daviso, A., Flexer, R.; Queen, R. & Meindl, R. (2011). Students with intellectual disabilities: Predictors of transition outcomes. *Career Development and Transition for Exceptional Individuals*, 34 (3), 132-141.
- Baker, E., Wang, M., & Walberg, H. (1994). The effects of inclusion on learning. *Educational Leadership*, 52, 33-35
- Benz, M., Lindstrom, L., & Latta, T. (1999). Improving collaboration between schools and vocational rehabilitation: The youth transition program model Improving collaboration between schools and vocational rehabilitation: The youth transition program model. *Journal of Vocational Rehabilitation, 13* (1), 55-63.
- Benz, M. R., Lindstrom, L., & Yovanoff, P. (2000). Improving graduation and employment outcomes of students with disabilities: Predictive factors and student perspectives. Exceptional Children, 66 (4), 509-529.

- Burgstahler, S. (2001). A collaborative model promotes career success for students with disabilities: How DO-IT does it. *Journal of Vocational Rehabilitation*, 16 (3-4), 209-216.
- Cole, C., Waldron, M., Majd, M. and Hasazi, S. (2004) Academic Progress of Students Across Inclusive and Traditional Settings. *Mental Retardation*, 42 (2), 136-144.
- Collaboration to Promote Self-Determination (n.d.). *Member* organizations. Retrieved from <u>http://thecpsd.org/who-we-</u> <u>are/partners/</u>
- Dunst, C. (2002). Family-Centered Practices: Birth through High School. Journal of Special Education, 36 (3), 139-47
- Dubberly, R. (2012) Community-Based Instruction (CBI) as a Component of a Successful Transition Plan for Students with Intellectual Disabilities. *Journal of the American Academy of Special Education Professionals*, 35-46. Retrieved from http://aasep.org/fileadmin/user_upload/Protected_Directory/JAASEP /JAASEP_ 2012/Winter_2012/CommunityBased_ Instruction_ Component_of_Successful_ Transition_Plan_ Students _w_Intellectual_Disabilities.pdf
- Edmondson, C. A., & Cain, H. M. (2002). The spirit of the Individuals with Disabilities
 Education Act: Collaboration between special education and vocational rehabilitation for the transition of students with disabilities. *Journal of Applied Rehabilitation Counseling*, 33 (4), 10-14.
- El Mouzan, M, Al Salloum, A, Herbish A, Qurachi, M, & Al Omar A. (2008). Consanguinity and major genetic disorders in Saudi children: a community-based cross-sectional study. *Annals of Saudi Medicine*, 28 (3),169-173.
- European Association of Service Providers for Persons with Disabilities (2013). 10 Best Practices in employment support for people with disabilities. Retrieved from http://www.ytporegon.org /sites/default/ files/fileattachments/best%20practices%2 Opublication% 20EAS%20007-13_ok.pdf
- Gartin, B. & Murdick, N. (2005). The IEP. Remedial and Special Education, 26 (6), 327-340.
- Gerrard, L. (1994). Inclusive Education: An Issue of Social Justice. *Equity* and Excellence in Education, 27, 58-67.

- Hunt, P., Farron-Davis, F. Beckstead, S., Curtis, D., & Goetz, L. (1994). Evaluating the effects of placement of students with severe disabilities in general education versus special education. *Journal of the Association for Persons with Severe Handicaps, 19* (3), 200-214.
- Jain, R., Thomasma, D. & Ragas R. (2002). Down syndrome: still a social stigma. *American Journal of Perinatology 19* (2), 99-108.
- Jameson, J. & McDonnell, J. (2010). Home and Community Living. In Pathways for Students With Intellectual and Developmental Disabilities (McDonnell, J & Hardman, M., Eds.) Newbury Park, CA:Sage Publications.
- Japan International Cooperation Agency Planning and Evaluation Department (2002). Country Profile on Disability: Kingdom of Saudi Arabia. Retrieved from http://siteresources. worldbank.org/ DISABILITY/Resources/Regions/MENA/JICA_Saudi_Arabia.pdf
- Katz, J., & Mirenda, P. (2002a). Including students with developmental disabilities in general education classrooms: Educational benefits. *International Journal of Special Education*, 17, 14–24.
- Katz, J., & Mirenda, P. (2002b). Including students with developmental disabilities in general education classrooms: Social benefits. *International Journal of Special Education*, 17, 25–35.
- Kim, K. & Turnbull, A. (2004). Transition to Adulthood for Students with Severe Intellectual Disabilities: Shifting toward Person-Family Interdependent Planning. *Research and Practice for Persons with Severe Disabilities (RPSD), 29* (1), 53-57.
- Lachapelle, Y., Wehmeyer, M., Haelewyck, M.C., Courbois, Y., Keith, K.D., Schalock R, Verdugo M. & Walsh, P. (2005). The relationship between quality of life and self-determination: An international study. *Journal of Intellect Disability Research*, 49 (10), 740-744.
- Lee, S., Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., & Little, T. D. (2008). Self- determination and access to the general education curriculum. *The Journal of Special Education*, 42, 97-107.
- Mansour, M. (2009). Employers' Attitudes And Concerns About The Employment Of Disabled People. *International Review of Business Research Papers*, 5 (4), 209-218
- McDonnell, J. & Hardman, M., Eds. (2010). Successful Transition Programs. Los Angeles: Sage Publications.

- McWilliam, R. (2006). What happened to service coordination? *Journal of Early Intervention, 28(3),* 166-168.
- National Down Syndrome Society (n.d.). Life After High School. Retrieved from <u>http://www.ndss.org/Resources/Transition-and-</u> Beyond/Life-After-High-School/
- Niazi, M, al-Mazyad A, al-Husain M, al-Mofada S, al-Zamil F, Khashoggi T, & al-Eissa, Y. (1995). Down's syndrome in Saudi Arabia: incidence and cytogenetics. *Human* Heredity, 45 (2), 65-69.

Noonan, P., Morningstar, M., & Erickson, A. (2008). Improving Interagency Collaboration: Effective Strategies Used by High-Performing Local Districts and Communities. *Career Development for Exceptional Individuals*, *31* (3), 132-143.

- Nota L, Ferrari L, Soresi S, Wehmeyer M. (2007). Self-determination, social abilities and the quality of life of people with intellectual disability. *Journal of Intellect Disability L Research, 51* (11), 850-865.
- Oertle, K. M. (2007). Interagency collaboration: The importance of rehabilitation professionals' involvement in transition. *The Journal of Rehabilitation*, 73, 36-44.
- Oregon Youth Transition Program (n.d.). YTP Selected as World's Top 10 Best Practices in Employment Support for People with Disabilities. Retrieved from <u>http://www.ytporegon.org/content/ytp-selected-worlds-top-10-best-practices-employment-support-people-disabilities</u>
- Pace, B. (2001). Down syndrome. *The Journal of the American Medical* Association, 285 (8), 1112-1119.
- PACER Center for the TA Network. (n.d.). VR Research in Brief. Retrieved from www.pacer.org/tatra/pdf/vrbrief-youth-centers.pdf
- Palmer, S. B., & Wehmeyer, M. L. (2003). Promoting self-determination in early elementary school: Teaching self-regulated problem-solving and goal-setting. *Remedial and Special Education*, 24 (2), 115-26
- Palmer, S. B., Wehmeyer, M. L., Gipson, K., & Agran, M. (2004). Promoting access to the general curriculum by teaching selfdetermination skills. *Exceptional Children*, 70, 427-439.

- Parent & Educator Partnership. (2001). Self Determination Synthesis Project. Retrieved from http://www.pepartnership.org /resources/ search/transition/self- determination-synthesis-project.aspx
- Parker, S. E., Mai, C. T., Canfield, M. A., Rickard, R., Wang, Y., Meyer, R. E., Anderson, P., Mason, C. A., Collins, J. S., Kirby, R. S., & Correa, A. (2010). Updated national birth prevalence estimates for selected birth defects in the United States, 2004–2006. *Birth Defects Research Part A: Clinical and Molecular Teratology*, 88, 1008– 1016.
- Renzaglia, A. & Hutchins.M. (1988). Establishing Vocational Training Programs for School-Age Students with Moderate ad Severe Handicaps. In Pueschel, S. (Ed.) *The Young Person With Down Syndrome: Transition From Adolescence to Adulthood* (109-127). Baltimore, MD: Paul Brookes Publishing Co.
- Southwest Educational Development Laboratory (1995). Inclusion: The Pros and Cons. *Issues... about Change*, 4 (3). Retrieved from <u>http://www.sedl.org/change/issues/issues43.html</u>
- Sweeden, B., & Carter, E. W., & Trainor, A. A., & Ditchman, N., & Owens, L. (2009). Community-based summer work experiences of adolescents with high-incidence disabilities. *The Journal of Special Education*, 45, 89-103.
- Turnbull, H. R., Beegle, G., Stowe, M. J. (2001). The core concepts of disability policy affecting families who have children with disabilities. *Journal of Disability Policy* Studies, 12 (3), 133-143.
- United States Department of Labor, Office of Disability Employment Policy (n.d.) *The Guideposts for Success*. Retrieved from <u>http://www.dol.gov/odep/categories/youth/</u>
- University of North Carolina, Charlotte. (2001). Self-Determination Synthesis Project. Final Performance Report.
- Villa, R, and Thousand, J., Eds. (2000). *Restructuring for Caring and Effective Education*. Baltimore, MD: Paul H Brookes Publishing Co.
- Wagner, M., Newman, L., Cameto, R., and Levine, P. (2006). The Academic Achievement and Functional Performance of Youth With Disabilities. A Report From the National Longitudinal Transition Study-2 (NLTS2). (NCSER 2006-3000). Menlo Park, CA: SRI International. Retrieved from <u>http://files.eric.ed.gov/fulltext/ED494936.pdf</u>

- Wehman, P. (2006) Integrated Employment: If Not Now, When? If Not Us, Who? *Research & Practice for Persons with Severe Disabilities*, 31 (2), 122–126.
- Wehmeyer, M., (1998). The Self Determination Focus of Transition Goals for Students with Mental Retardation. Career Development for Exceptional Individuals, 21, 75-86,
- Wehmeyer, M., Agran, M., Palmer, S., Mithaug, D., & Blanchard, C. (1998). *A teacher's guide to the use of The Self-Determined Learning Model of Adolescent version*. Arlington, TX: The ARC of the United States.
- Wehmeyer, M. L., & Palmer, S. (2003). Adult outcomes for students with cognitive disabilities three years after high school: The impact of self-determination. *Education and Training in Mental Retardation and Developmental Disabilities*. 38, 131-144.
- Wehmeyer, M., Palmer, S., Agran, M., Mithaug, D., & Martin, G. (2000). Promoting causal agency: the self determined learning model of instruction. *The Council for Exceptional Children*, 66 (4), 439-453.
- Wehmeyer, M., & Schwartz, M. (1997). Self-Determination and Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation or Learning Disabilities. *The Council for Exceptional Children, 63* (2), 245-255.
- Wehmeyer, M., & Schwartz, M. (1998). The Relationship Between Self-Determination and Quality of Life for Adults with Mental Retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, 33 (1), 3-12.
- Wehmeyer, M., Palmer, S., Agran, M., Mithaug, D. E., & Martin, J. E. (2000). Promoting causal agency: The self-determined learning model of instruction. *Exceptional Children*, 66, 439-453.
- Weijerman, M & Winter, J (2010). Clinical practice. The care of children with Down syndrome.. *European Journal of Pediatrics*, 169 (12), 1445–52.
- Wood, W., Karvonen, M., Test, D., Browder, D. & Algozzine, B. (2003).
 Promoting Student Self-Determination Skills in IEP Planning. *TEACHING Exceptional Children, 36* (3), 8-16.

Wrightslaw (2006). IDEA 2004 Regulations: Summary of Changes. Retrieved from http://www.wrightslaw.com /idea/law/idea. regs. sumry. chngs.pdf