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ROBERT M. HODAPP

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INTERNATIONAL REVIEW OF RESEARCH IN MENTAL RETARDATION

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INTERNATIONAL REVIEW OF RESEARCH IN MENTAL RETARDATION

PREFACE

With this volume, Volume 38, I assume the job of general series editor of the *International Review of Research in Mental Retardation*. Ably edited since Volume 20 by Laraine Masters Glidden, the *International Review* has continued its role as the intellectual disability field's most important, prestigious publication devoted to state-of-the-art research reviews. It is today stronger than at any time since its founding in 1966. Now is a great time to accept the editorial baton.

Although accepting any baton evokes visceral reactions from my track days many years ago, the baton metaphor also serves to highlight several field-related issues. At the first, most basic level, the passing of the editorial baton highlights continuity with the field's past. For 43 years, the *International Review* has published the best of scientific work related to intellectual and developmental disabilities. Over 300 articles have been published in 37 volumes. Virtually every major worker in the intellectual disabilities field has published in its pages, under the direction of three series editors. These editors—Norman Ellis (Volumes 1–11; 1966–1982), Norman Bray (with Ellis for Volumes 12–14, separately for Volumes 15–19; 1984–1997), and Laraine Masters Glidden (Volumes 20–37; 1999–2009)—have carefully, tactfully run the good race. I am beholden to each of them for their record of achievement and for the high esteem in which the *International Review* is universally held.

Accepting the editorial baton also engenders thoughts of the future. Indeed, at various points over the past decade, researchers have questioned the viability of the research field that examines intellectual disabilities. As participants at the annual Gatlinburg or other conferences quickly notice, the field of research specifically devoted to intellectual disabilities is very small, with active researchers probably numbering no more than 300. Issues of tenuous grant support (Baumeister, 1997), an aging corps of researchers, and the need to train and nurture the next generation have all preoccupied researchers both old and new. As the title of a recent article asks, "Who will lead the mental retardation field in the year 2020?" (Havercamp, Tasse, Lunsky, & Garcin, 2003).

But as this and other *International Review* volumes illustrate, the future may not be quite so bleak. Over the past several decades, this small but hardy band of researchers has expanded the nature and scope of disability work. As noted below, this group has become increasingly international and, over time, larger in number. To this more established group, one can now add a growing cadre of younger researchers. These younger researchers, now knee-deep in balancing new jobs, marriages, children, courses, students, studies, grants, and tenure, are also opening areas that until now have received little attention.

Working together, then, the more established and younger researchers are expanding the boundaries of the field itself. Although many measures of such expansion are possible, one simple measure concerns the numbers of issues of established journals and the founding of new journals. As of 2005, the *Journal of Intellectual Disabilities Research*, the flagship journal of the International Association for the Scientific Study of Intellectual Disabilities (IASSID), expanded from 8 to 12 issues each year and new journals have been founded that connect intellectual disabilities to policy-related research (*Journal of Policy and Practice in Intellectual Disabilities*, begun in 2004), origins and development of disorders (*Journal of Neurodevelopmental Disorders*, 2008), psychopathology (*Journal of Mental Health and Intellectual Disabilities*, 2008), and health (*Disabilities and Health Journal*, 2008). In becoming series editor, then, I am reminded of Norman Ellis' (1966) declaration, in the Preface to the *International Review's* first volume, that "Behavioral research pertaining to mental retardation has suddenly burgeoned. Indeed, it seems reasonable to speculate that more research has occurred in this field in the past 10 years than in all previous years" (p. vii).

So what, exactly, does Volume 38 portend? Although the easy answer is a little of everything, I prefer to characterize this issue as representing a continuum, from the latest expansions of more established areas to initial forays into unchartered territories. In a provocative expansion, Julie Lounds Taylor applies life span development theories to the many changes that families experience as their adolescents with disabilities transition into adulthood. Although transition has existed as a subfield within Special Education for decades, few studies exist on the families of these young adults, even as the transition from school-to-adult services is among the most important changes faced by these young adults and their families. Returning to Erikson and to attachment theory, Taylor explores the ways that understanding normative changes might help us to identify similarities and differences that occur in families when their adolescent with disabilities enters adulthood.

Similar expansions—the latest word on more established topics—can be seen as well in other contributions. In their review of intervention approaches to young children with autism, Stephanny Freeman, Tanya Paparella, and Kelly Stickles make the case for more individualized approaches, using as a case example their own Early Child Partial Hospitalization Program (ECPHP) at UCLA. In many ways, Freeman and colleagues are presenting the next generation of intervention approaches in this area, going beyond comprehensive or targeted treatments, intervention- or method-specific approaches to instead advance a more eclectic approach. Featuring their own type of response-to-treatment model, Freeman et al. individualize instruction based on each child's most recent progress, correcting and changing as they go along. Their initial findings seem especially promising.

Other chapters also present the latest extension on more established topics. Naznin Virji-Babul and Dan Weeks go beyond the distinctions among cognition, perception, and action to join these three for children and adults with Down syndrome. Reviewing the latest in brain technology, Virji-Babul and Weeks present findings that may lead to more effective, tailored interventions for these individuals. So too does one see an intervention focus in Johannes Rojahn and Lisa Meyers' update on dual diagnosis. As we increasingly appreciate that many individuals with intellectual disabilities have both intellectual impairments and psychiatric disorders, an entire subdiscipline—highlighted by Rojahn's 2008 founding of the *Journal of Mental Health and Intellectual Disabilities*—has now sprung up to address these issues.

If such articles can be considered the latest word on more established topics, so too does this volume include beginning forays into unchartered lands. At its most concrete, the term "unchartered lands" refers to such actual countries as China, Vietnam, and Korea. Presented by younger researchers who are creating a field of disability research where none existed, these three contributions highlight both the differences and similarities of the status of children with disabilities and their families within the context of each society. To choose but one example per chapter, Peishi Wang shows how China's single-child policy affects children with disabilities, sibling and parent attitudes, and how children with disabilities are perceived in the society; Emily D'Antonio and Jin Shin how the aftereffects of the Vietnam war continue to affect those with disabilities and their families; and Sun Young Ryu how the Korean history of schools has led to relatively advanced services for children with physical disabilities, even as services are more delayed for children with intellectual disabilities. Other examples could be cited as well, highlighting the ways in which the status of persons with disabilities is partly dependent on the specific country and culture.

At the same time, however, similarities also exist, both across these three countries and from these to other lands. In all countries, then, mothers of children with (vs. without) disabilities experience higher levels of stress, and issues of poverty and of rural versus urban living enter in. Difficulties in developing sufficient amounts of service (by trained personnel) seem common to all three countries, as is the universal problem in accessing and receiving such appropriate, high-level services by children (or adults) and their families. It is instructive to juxtapose those problems common to only one society and those that seem universal. If indeed 85% of all children with disabilities live outside of Western, industrialized countries—the countries in which most research has taken place on children with disabilities and their families—we do well to "charter" these unchartered lands.

Less concretely, so too do other contributors venture into unchartered lands. Patricia Noonan Walsh and Roy McConkey, for example, examine the entire issue of the health of individuals with disabilities. Bringing to this issue an international, human rights perspective, Walsh and McConkey describe the nature of health disparities, why they might occur, and how a research agenda is critical to examining and correcting such health inequalities. Although the entire topic of health care seems both complicated and controversial, Walsh and McConkey succeed in joining today's news to the disability community, both here and across the world.

In another foray into unchartered lands, Shihfen Tu, Donna Doherty, Kathryn Schilmoeller, and Gary Schilmoeller examine individuals with agenesis of the corpus callosum (ACC). Although a topic rarely if ever considered within research journals devoted to intellectual disabilities, many individuals with ACC have intellectual and other disabilities. Beyond the basics, Tu and her colleagues describe the many areas of functioning affected by ACC, as well as promising intervention approaches.

There you have it: nine excellent contributions, ranging widely in topics and approaches, by established and newer researchers. But before ending, let me add again a few notes of thanks. Having completed one volume as series editor, I have an even greater respect for Laraine Glidden's decade of hard work for the *International Review*, her perseverance, and her good humor. To me personally, Laraine has been exceptionally generous with her time, information, and advice. Her major bit of advice—that I will enjoy getting to know and working with contributors who I would never have known otherwise—has already come true. Such relationships, alone, seem worth the price of admission. More subtly, though, I value Laraine's implicit assertion—to me and to so many others in the field—that I can succeed at this and at other endeavors, and that it is all definitely worth the try. Thanks, too, to Tara Hoey, Mica Haley, Gayathri Venkatasamy, and all of the other seasoned, savvy professionals at Elsevier Press, who have made this rookie editor's life so much easier. I would as well like to thank reviewers for this issue, especially Nancy Miodrag, Rick Urbano, and Elisabeth Dykens. Last (but in no way least), I thank the nine sets of contributors to this volume. Squeezed into incredibly busy lives, each has completed (and revised) thoughtful, excellent contributions. If it takes a village to raise a child, it takes an international village—of diverse professionals from subdisciplines within and outside of the disability field—to raise a volume.

And. . .we're off. Time to lean into that first turn. . .

ROBERT M. HODAPP

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CHAPTER ONE

THE TRANSITION OUT OF HIGH SCHOOL AND INTO ADULTHOOD FOR INDIVIDUALS WITH AUTISM AND FOR THEIR FAMILIES

Julie Lounds Taylor*

Contents

Abstract

This chapter focuses on the impact of exiting high school for individuals with autism spectrum disorder (ASD) and their families. First, general developmental theories that can assist in guiding research on the transition to adulthood are explained and applied to families of individuals with ASD. Next, extant research on the impact of transition out of high school and into adulthood for individuals

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with ASD and for their families is summarized. Finally, a number of directions for future research are discussed.

1. INTRODUCTION

> "He lost everything then (when he exited high school). All the training was gone. They had worked on stimming, now it's back. He had worked part time with a job coach. Now he can't do that. There is no funding."
>
> - Mother of a 24-year-old son with ASD

> "I worry about him, where he'll be in life down the road. Worry about him financially; him gaining friendships and not being lonely."
>
> - Mother of a 19-year-old son with ASD

In 2007, the United States Department of Education reported that there were nearly 257,000 children and adolescents in the primary and secondary school systems with a diagnosis of autism spectrum disorder (ASD), a neurodevelopmental disorder beginning before the age of 3 and characterized by impairments in communication and social interaction, and the presence of restricted and repetitive behaviors (IDEAdata.org, 2009). The rapid rise in the number of children diagnosed with ASD began in the early 1990s (Gurney et al., 2003) and children from that generation are now exiting the school system, putting an extreme burden on an already over-taxed adult service system (Howlin, Alcock, & Burkin, 2005).

Although this increase in the prevalence of ASD may be due in large part to diagnostic substitution (Shattuck, 2006), nevertheless many of these adolescents and young adults are in need of formal and informal supports during and after transition. As they exit high school and transition to adulthood, individuals with ASD lose the entitlement to many (and sometimes all) of the services that they received while in the school system. As demonstrated by the previous quotes, in most cases these young adults enter a world of adult services plagued by waiting lists and a dearth of appropriate opportunities to achieve a maximum level of adult independence. When services are inadequate, parents often assume primary responsibility for meeting their son or daughter's needs (Howlin, 2005). As more and more individuals with ASD leave the school system and transition into adulthood and the adult service world, it is critical to understand the factors that promote an optimal transition process. Furthermore, as service providers rely more heavily on parents to coordinate services, it becomes increasingly important to understand how mothers and families are affected by this transition.

There is little empirical research addressing how the transition to adulthood might affect families of individuals with ASD; however, the clinical and anecdotal evidence indicates a range of possible reactions.