We begin this article by examining the role of intellectual disabilities within child psychiatry, highlighting the relatively steady role of disabilities and the recent movement to examine behavior in specific genetic syndromes. We next propose five questions for future work. Questions relate to (1) specifying the nature of gene–brain–behavior connections; (2) delineating environmental effects and gene–environment interactions; (3) understanding behaviors, physical characteristics, health issues, and other personal characteristics by which children with intellectual disabilities influence others; (4) clarifying the roles of gender and aging in behavioral functioning; and (5) working to improve pharmacological, educational, and other interventions and supports for children and their families. Although great advances have occurred over the past 50 years, intellectual disability research lags behind other areas of child psychiatry; much remains to be discovered that might help these children.

Keywords: Behavioral phenotype, gene–brain-behavior relations, GE correlation, demographics, gender, aging. Abbreviations: ERP: event-related potential; MRI: magnetic resonance imaging.

Like the 50th birthday of a person, the 50th birthday of a journal is an occasion for looking both backward and forward. Looking backward, one wants to know how one got to the current moment, which decisions, influences, practices, and experiences have made us what we are today. But we also want to contemplate the future, and plan strategies to make that future as bright as possible.

JCPP’s 50th birthday also involves looking backward and forward. As we hope to demonstrate, the first 50 years of work in intellectual disabilities feature areas of enormous advances, many of which can be shown in the pages of this journal itself. But our goal is not to survey the past, but instead to use the past as an entryway into the future. Thus, after a brief description of past work on intellectual disabilities, we discuss five areas of future work.

Intellectual disabilities and JCPP: the first 50 years

Although articles in JCPP reflect the field’s early days, research in intellectual disabilities predates the birth of this journal. In both the UK and the US, small but continuing fields existed prior to the 1960s. As Tizard (1966) noted in his 1965 Chairman’s Address (published in JCPP), ‘The numbers engaged in research in mental subnormality have always been small’ (p. 8); counting all full- and part-time researchers, as of 1960 the UK’s field of intellectual disabilities probably consisted of no more than 12–15 researchers. In addition, research in intellectual disabilities generally occupied a lower status in the hierarchy of topics examined in child psychiatry. Tizard (1966) notes that, ‘on the whole it has not been a fashionable field for research’ (p. 8) and various researchers – over an 80-year span – have invoked the Cinderella metaphor to suggest that the field would shortly take its rightful place at the mental health ball (Potter, 1927; Tarjan, 1966; King, State, Shah, Davanzo, & Dykens, 1997).

Still, as shown by Table 1’s tally of articles on intellectual disability published in JCPP since its inauguration, over the years intellectual disabilities has continued to hold a steady place within child psychiatry. Overall, one sees slightly increasing numbers of articles published on the topic from one five-year time-span to the next. But Table 1 also shows a change in the publication of etiology-based articles. Except for Down syndrome, etiology-based studies were totally absent before the mid-1980s. Reflecting a joining of intellectual disability’s ‘two cultures’ of biomedical and level-of-impairment approaches (Hodapp & Dykens, 1994), these studies also introduced into the disabilities field many researchers from allied fields, and this cross-disciplinary influx has helped invigorate intellectual disability research.

Where are we now? On one hand, the field has not re-approached its high-water mark during and after the Kennedy Administration, when money and prestige were at their highest. At that time, Ellis (1966) proclaimed that ‘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). In addition to lessened prestige compared to the 1960s, two additional problems persist. First,
Table 1 JCPP articles devoted to intellectual disability (ID) and specific etiologies since 1960

<table>
<thead>
<tr>
<th>Years</th>
<th>Total N</th>
<th>N of articles on ID</th>
<th>Empirical articles on ID</th>
<th>Disorders examined</th>
</tr>
</thead>
<tbody>
<tr>
<td>1960–64</td>
<td>102</td>
<td>5 (4.9%)</td>
<td>3</td>
<td>ID: 5</td>
</tr>
<tr>
<td>1965–69</td>
<td>96</td>
<td>7 (7.29%)</td>
<td>6</td>
<td>ID: 7</td>
</tr>
<tr>
<td>1970–74</td>
<td>107</td>
<td>6 (5.61%)</td>
<td>6</td>
<td>ID: 2; DS: 4</td>
</tr>
<tr>
<td>1975–79</td>
<td>158</td>
<td>7 (4.43%)</td>
<td>6</td>
<td>ID: 6; DS: 1</td>
</tr>
<tr>
<td>1980–84</td>
<td>196</td>
<td>11 (5.61%)</td>
<td>10</td>
<td>ID: 7; DS: 4</td>
</tr>
<tr>
<td>1985–89</td>
<td>346</td>
<td>25 (7.23%)</td>
<td>16</td>
<td>ID: 17; DS: 5; FX: 2; FAS: 1</td>
</tr>
<tr>
<td>1990–94</td>
<td>413</td>
<td>22 (5.33%)</td>
<td>14</td>
<td>ID: 15; DS: 4; FX: 2; FAS: 1</td>
</tr>
<tr>
<td>1995–99</td>
<td>467</td>
<td>11 (2.36%)</td>
<td>9</td>
<td>ID: 5; DS: 2; PW: 2; WS: 2</td>
</tr>
<tr>
<td>2000–04</td>
<td>467</td>
<td>21 (4.5%)</td>
<td>14</td>
<td>ID: 7; DS: 5; PW: 1; WS: 5; FX: 3</td>
</tr>
<tr>
<td>2005–07</td>
<td>365</td>
<td>13 (3.56%)</td>
<td>11</td>
<td>ID: 6; DS: 2; PW: 1; WS: 2; FX: 1; AS: 1</td>
</tr>
</tbody>
</table>


researchers worry about sufficient funding to facilitate major research advances (Baumeister, 1997). Second, the field continues to be concerned about its ability to produce a critical mass of new researchers (Havercamp, Tasse, Lunsky, & Garcin, 2003).

Yet hopeful trends are also apparent. As the editor of the American Journal on Mental Retardation notes, compared to earlier decades near-equivalent numbers of new researchers are probably entering the field, but ‘there may be many more young scientists in the biological sciences or in neuroscience studying developmental disabilities than in years past’ (Abbeduto, 2008). In addition, some journals have expanded in their numbers of issues (e.g., Journal of Intellectual Disability Research) and several new journals have recently been inaugurated (Disability and Health Journal; Journal of Policy and Practice in Intellectual Disabilities; Journal of Neurodevelopmental Disorders; Journal of Mental Health Research in Intellectual Disabilities). These trends reflect cautious optimism for disability-based work in the larger psychological or psychiatric research landscape.

Five questions for future research

Although we see many diverse trends as we consider the future, five overarching topics stand out for future study. These questions encompass a variety of disciplines and straddle the divide of basic and applied research.

1) How can intellectual disabilities inform gene–brain–behavior relationships?

Although interest in genetics is relatively new to most behaviorally oriented researchers, recent progress is undeniable. Such progress has occurred in measuring behavioral phenotypes (Dykens, 1995), or the ways in which different genetic syndromes predispose children to show specific profiles or trajectories (Dykens, Hodapp, & Finucane, 2000; Einfeld, 2004), and in connecting behavioral phenotypes to regions of the brain or the genome. Groundbreaking work is now occurring that links molecular, brain, and behavioral findings in fragile X, Rett, Cardio-facial, Down, Williams, Prader-Willi, and Angelman syndromes (for reviews see Schaer & Eliez, 2007; Venkitaramani & Lombroso, 2007).

Although numerous examples exist, we here discuss one instance of gene–brain–behavior connections. Using ERPs to examine brain responses to pictures of food, Key and Dykens (2008) showed that, while all individuals with Prader-Willi syndrome analyzed food stimuli quickly, the two genetic subgroups – those with deletions on chromosome 15 versus those with maternal uniparental disomy – diverged in whether they most attended to food composition (single vs. combined foods) or suitability to be eaten (matched, mismatched or contaminated foods), which related to food-seeking behaviors. Using ERP or MRIs, recent findings tie specific brain regions or functions to such phenomena as Alzheimer’s dementia in Down syndrome (Zigman & Lott, 2007), poor visuospatial processing in Williams syndrome (Hoef et al., 2007), and the onset of psychiatric disturbance in velocardiofacial syndrome (Gotthelf, 2007).

Although research on these neurogenetic syndromes is propelling the field forward, we here inject a few cautionary notes. First, etiology-based studies remain limited in the numbers of syndromes examined. Currently, behavioral studies exist for 15–20 genetic syndromes, even as over 1,000 conditions have been associated with intellectual disabilities. Although many of these conditions are quite rare, they nonetheless may prove to be informative for gene–brain–behavior understanding. Second, most neuroimaging or behavioral studies are cross-sectional and examine relatively small numbers of participants whose ages often vary widely. Third, in light of differing behaviors across syndromes, functional neuroimaging studies necessarily differ one from another (Schae & Eliez, 2007), which limits comparisons between and within syndromes. Finally, studies focus on only selected aspects of maladaptive behavior-psychopathology, cognitive profiles, or language, with less attention to the ‘whole child’ and

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to how aspects of a syndrome most affect children in their everyday lives.

Neurogenetic disorders aside, few studies in intellectual disabilities have examined polygenic issues, although this state of affairs may be changing. For example, behavior geneticists have long concluded that approximately 50% of the variation in IQ is due to hereditary factors, 50% to environmental factors (Plomin, 1999). What, however, are heritability estimates among children with low IQ? Comparing identical versus fraternal twins on preschool tests, two studies reach different conclusions: that, compared to heritability among higher-IQ children, heritability at low IQ levels is the same (Petrell et al., 1997) or that it is increased (Spinath, et al., 2003). Over the next few years, studies will likely arise that resolve these conflicting findings, as well as that examine heritability for components of intelligence, language, personality, and other aspects of behavior among children with mild intellectual disabilities. Similarly, we do not yet know whether one of behavior genetics’ most intriguing findings – that for many behavioral traits heritability rates rise (instead of decline) as children get older (Plomin & Spinath, 2006) – will replicate for children with mild intellectual disabilities.

Already we are witnessing a blending of research on genetic syndromes and behavior genetics. This approach might ask, for example, the extent to which genetic markers previously associated with anxiety in non-disabled populations make even more likely anxiety in children with Williams syndrome (Dyke, 2003). In short, work on behavior genetics – historically focused on typical children – and work on behavioral phenotypes – historically focused on children with genetic syndromes – are rapidly coming together.

2) What are the effects of the child’s environment on various outcomes?

Like researchers in other fields, disability researchers are increasingly appreciating that one must be concerned with both genes and environment, and on the complex interactions between the two. To date, however, the disability field has not fully exploited advances made in understanding environmental effects.

A first area of interest to children with disabilities concerns gene–environment, or GE, interactions. GE interactions highlight the ways in which specific environments do not affect everyone equally, but instead most affect those who already show certain genetic susceptibilities. One potential example for intellectual disabilities involves the connections between child abuse and subsequent anti-social behavior. As Caspi et al. (2002) demonstrated, only those children who experienced child abuse and had a particular variant of the MAOA gene were at high risk of becoming anti-social; neither child abuse nor the presence of the MAOA variant, by itself, was usually enough for anti-social behavior to develop.

Given that, compared to non-disabled children, children with intellectual disabilities are from 4–10 times more likely to be abused (Fisher, Hodapp, & Dykens, 2008), one might search to determine if similar connections also hold true in the population with intellectual disability.

Beyond child abuse per se, the general concept of GE interactions should prove helpful to disability researchers. Especially for children with mild intellectual disabilities and for those with genetic syndromes, almost all outcomes are probabilistic, with not every individual showing an expected outcome. Some variability in outcome may be associated with polymorphisms that alter the expression or function of genes, and these may interact with poor or stressful environments that lead to less-than-optimal developmental outcomes.

In this vein, a critical area in need of work is the question of how poverty impacts the outcomes of children and adults with intellectual disabilities and their families. Children with disabilities more often reside in single-parent, poorer, and minority families (Emerson, 2007; Fujiura & Yamaki, 1997). Despite the far-reaching effects of poverty on maternal and child health or mental health, most research to date includes children in families that are two-parent, middle- or upper-middle class, and from the majority culture.

From the opposite direction, will there be protective environments for children with intellectual disabilities? From the literature on risk and resilience, we know that an alert, affectionate, and sociable child temperament, optimal use of one’s skills and talents, and the presence of one or more caring adults all help at-risk children to become resilient (Werner, 1993). But to what extent do such protective factors operate among children with disabilities, and do such factors help to account for the widely discrepant outcomes that often occur for two children of similar IQ levels? At present, we do not know.

3) How do children affect their parents, siblings, and families?

In the past two decades, perceptions have changed dramatically as to how children with intellectual disabilities affect others. From an almost exclusive focus on the ‘bad things’ that happen to families of children with disabilities, modern researchers consider these children as stressors in their family systems. On average, only slightly negative outcomes accrue, and only in certain families. Mothers of children with disabilities appear only slightly more depressed than are mothers of non-disabled same-aged children (Singer, 2006), and divorce rates of couples raising children with intellectual disabilities are only slightly higher overall (Risdal & Singer, 2004) – divorce rates may even be lower than...
population rates when the child has Down syndrome (Urbano & Hodapp, 2007). Many family members also report life-enhancing benefits from raising their children with intellectual disabilities (Taunt, & Hastings, 2002). The negative effects of raising the child with intellectual disabilities may have been over-emphasized.

But most families do seem affected – either negatively or positively – by raising their child with disabilities, and one might ask what constitutes the active ingredients of the child’s effects on others. This question is more difficult to answer than it seems, and each of the following has been nominated as a child influence on parental stress, behaviors, or emotions:

- **Maladaptive behavior.** Parents experience stress in the face of high levels of maladaptive behavior, both with children with intellectual disabilities more generally (Blacher & McIntyre, 2006) and when children have a specific genetic syndrome (Hodapp, Dykens, & Masino, 1997). Even compared to other possible predictors of maternal functioning, the amount or severity of child maladaptive behavior typically emerges as a robust predictor of maternal stress and health.

- **Cognitive-linguistic profiles.** Although mothers of children with or without disabilities typically tailor their language to match their child’s mental age, data are scarce on how children’s cognitive strengths or weaknesses influence parental behavior. In one study, mothers of children with Prader-Willi syndrome provided less support than other mothers in helping their child solve a task that was geared toward their child’s strength in puzzles (Ly & Hodapp, 2005). Other work shows how weaknesses in means-ends or strategic thinking in young children with Down syndrome may evolve into these children turning to others for solutions, and planting seeds for the overly social personalities often noted in this population (Fidler, 2006).

- **Health problems.** Children with intellectual disabilities are often sicker than non-disabled children and the types and timing of health issues may differ in specific conditions. For example, approximately half of infants with Down syndrome show congenital heart defects, and hospitalizations of infants with the syndrome (often for respiratory problems) are common in the first year of life (So et al., 2007). Having a child with disabilities may also relate to increased levels of sickness among family members (Hogan, Park, & Goldscheider, 2003).

- **Facial appearance.** Infantile facial characteristics elicit nurturant feelings from surrounding adults, and children with specific genetic syndromes show differences in the degree to which they possess such facial appearances. Comparing three groups with differently ‘babylike’ faces (Down syndrome, 5p syndrome, non-disabled age-mates), adults showed more nurturant reactions to more babylke faces, both across groups (DS > other groups) and for more-versus-less babyfaced children within the Down syndrome group (Fidler & Hodapp, 1999).

- **Infant crying and irritability.** Some infants with intellectual disabilities display heightened irritability, aversive crying, or more subdued cries, and each is a risk factor for child abuse, or for aberrant mother–child interactions (Ammerman & Patz, 1996).

- **Timing and certainty of diagnoses.** Specific conditions are diagnosed at different ages in the child’s life, and such differences in timing of diagnosis may affect others. Comparing siblings of children with intellectual disabilities to siblings of children with psychiatric illnesses (e.g., schizophrenia), Seltzer et al. (2004) highlighted differences in the timing of diagnosis to siblings and other family members. Conversely, parents of children with no clear diagnosis for their child’s intellectual disabilities fared worse than did parents of children who had an identified diagnosis (Goldberg, Marcovitch, MacGregor, & Lojkasek, 1986).

4) **What are the effects of gender and aging?**

Although it has long been known that males are over-represented among those with intellectual disabilities, few studies examine sex differences. In a review of articles in the field’s two leading journals (American Journal on Mental Retardation and the Journal of Intellectual Disability Research), only about one-quarter of articles published over a five-year period reported both the gender breakdown of their participants and analyzed their behavioral data to determine whether sex-differences existed (Hodapp & Dykens, 2005). For the majority of articles in both journals, the gender breakdown of participants was reported, but no mention was made as to whether the researchers looked for possible gender differences. In the remaining 10–20%, no mention was made of gender.

Although not always found when examined, a few gender differences have been reported in Down syndrome and Williams syndrome. Compared to older men with Down syndrome, older women may be somewhat more prone to show the clinical symptoms of Alzheimer’s disease (Ward, 2004) and this risk may be associated with lowered levels of estrogen. Similarly in Williams syndrome, a group that generally exhibits heightened anxiety, fears, and phobias (Einfeld, Tonge, & Florio, 1997), an interaction seems to exist between gender and age. Comparing 6–12-year-old children to adolescents–adults aged 13–18 and 18+ years, Dykens (2003) found that adolescent girls and adult women became more fearful overall, suggesting an age-related,
increased vulnerability in women to anxiety and fears.

With such scant research attention to gender, it is unclear how or if gender effects seen in the general population play out in those with intellectual disabilities. For example, women are more apt to manifest depression than men, but gender differences in depression are not generally reported in those with intellectual disabilities. If a lack of gender differences in depression is indeed the case, then this finding might call into question how we think about the causes of depression in the general population.

It seems obvious that intellectual or developmental disabilities involve development, but here we note an urgent need to inject a developmental perspective into studies of developmental disabilities. Most behavioral or psychiatric studies in people with developmental disabilities are cross-sectional—they focus on one or another discrete age group, compare behaviors across different syndromes or diagnostic groups with little regard for the age-related features in each group, or examine how different genotypes of the same syndrome are associated with behavior, regardless of age. While longitudinal studies are challenging and costly, key questions regarding development can only be answered by charting how people with or without a known etiology change and evolve over the course of time.

Examples abound of such changes in young children with specific genetic etiologies. Across the childhood years in Down syndrome, percentages rise of young children who show receptive language abilities in advance of expressive abilities (Abbeduto, Warren, & Conners, 2007; Chapman & Hesketh, 2000). Boys with fragile X syndrome generally show higher-level abilities in simultaneous processing than in sequential processing, yet older boys with fragile X syndrome show this simultaneous-over-sequential pattern to a much more pronounced degree (Hodapp, Dykens, Ort, Zelinsky, & Leckman, 1991). Children with Williams syndrome show only slight gains in visuospatial skills, and a much steeper upward slope in language skills, such that an already weak area becomes progressively weaker, and an already strong area becomes progressively stronger (Jarrold, Baddeley, Hewes, & Phillips, 2001).

Beyond the childhood years, studies are more sporadic, and surprisingly few focus specifically on adolescence. In contrast, older adults with Down syndrome have been rigorously studied, primarily in relation to the well-established ties between Down syndrome and Alzheimer’s disease. As a result, we know a great deal about aging in Down syndrome, but much less about aging in other disorders, or in people with intellectual disabilities in general.

Even so, similar to the general population, more people with intellectual disabilities are living longer. In the US alone, current estimates are that 526,000 Americans with disabilities are 60 years or older, and that number is expected to triple—to over 1.5 million—by 2030 (National Center for Family Support, 2000). Given that 60% of these adults are cared for in the family home by aging parents, this trend has implications for siblings who assume care, and for shifts in how we provide medical, mental health, and other supports for older adults with intellectual disabilities (Walsh, 2005).

5) How can we optimize interventions or supports?

Clinicians, educators, families, and researchers all aim to optimize the life successes of children or adults with disabilities, and we end with considerations that might facilitate positive outcomes. In special education, most interventions might be considered ‘generic,’ with little attention to characteristics of the child with intellectual disabilities (Fuchs, 2006). Although calls have been made to tailor interventions to the cognitive-linguistic profiles, trajectories, or maladaptive behaviors of the child’s diagnosis or genetic syndrome (Hodapp & Fidler, 1999), special educators have mostly ignored such recommendations. The recommendations themselves also require more rigorous empirical tests. A further educational push in the years ahead is post-secondary and life-long learning programs for adults with intellectual disabilities; these programs hold much promise for enhancing academic, social, and employment skills.

Focusing on psychiatric or behavioral/emotional problems, professionals now agree that, compared to general population norms, children and adults with intellectual disabilities are much more likely to suffer from maladaptive behavior and psychiatric conditions. Although rates vary from study to study, about 40% of all persons with intellectual disability show emotional and behavioral issues that markedly interfere with their everyday lives (Dykens, 2000).

Faced with this marked co-occurrence of intellectual disability and psychopathology (so-called ‘dual diagnosis’), considerable progress in identifying psychopathology has been made in training mental health workers about these co-occurring conditions, and in publishing validated assessment tools to identify these problems (e.g., checklists, interviews, adapted diagnostic criteria; see Fletcher, Loschen, Stavrakaki, & First, 2007). We now need to use these tools to identify people at high or low risk for developing psychopathology, so that we can tailor treatment and prevention programs accordingly (Dykens, 2000). As well, these measures can be used in the service of treatment outcome, including the impact of psychotropic medications, or novel trials that stem from new insights into the neurobiology of specific disorders.

Interventions could also be made more effective by ensuring that they are culturally informed and culturally sensitive. Studies relating ethnicity to disability are in their infancy (Hatton, 2002).
Researchers have examined such topics as health in US Hispanic families of children with disabilities (Magaña & Smith, 2006), or aspects of interactions between mothers and children with disabilities in Asian-American families (Ly, 2008), but more work is needed on culturally sensitive interventions that optimize child and family well-being.

Beyond these measurement and cultural concerns, interventions could also benefit from rigorous epidemiological approaches that track demographic changes in people with disabilities (Canfield et al., 2006; Hodapp & Urbano, 2008), and their co-occurring medical or psychiatric problems at the population level. Researchers in intellectual disabilities have yet to catch up to their epidemiological colleagues (Hodapp & Urbano, 2007), who have long examined basic prevalence and correlates of numerous child psychiatric conditions, as well as the public health burden of such conditions (Costello & Angold, 2006). Similar approaches for identifying the public health and mental health impact of intellectual disabilities are critical for allocating appropriate resources for disability interventions or treatment programs.

Future work will also intervene to change more real-world outcomes for children with intellectual disabilities and their families. Such outcomes for the offspring with intellectual disabilities might include graduation from school, accessing community venues or events, and reducing hospitalizations, emergency room use, or getting arrested. For parents, outcomes might include choices to move, divorce, change jobs, start or stop working or go back to school. For adult (female) siblings, who most often will assume caretaking responsibilities for their brother/sister with disabilities, outcomes might include where to live and how (and when) to embark on careers, marriages, child-bearing, or friendships (Seltzer et al., 2005). Some of these real-world indices are embedded in quality of life measures, and we would do well to use such quality of life indices as outcome measures of specific interventions.

With enhanced quality of life as the endpoint, are evidence-based treatments used to treat psychiatric disorders in the general population also effective in people with intellectual disabilities? We do not know, as few clinical trials have been performed on persons with intellectual disabilities. Still, at least a few such studies exist on specified topics. We note, for example, Prasher et al.’s (2002) double-blind study of donepezil (i.e., Aricept) and Aisen et al.’s (2005) multicenter trial of the effects of vitamin E, both with adults with Down syndrome. Similarly, Khemka, Hickson, and Reynolds (2005) showed that an abuse-prevention curriculum was effective in helping women with intellectual disabilities improve on measures of knowledge, decision-making, and empowerment. Overall though, few studies exist on therapeutic interventions with children or adults with intellectual disabilities, and most intervention studies of psychiatric conditions or adverse environments (e.g., abuse) exclude from their samples children or adults with intellectual disabilities (Fisher, in press).

Nevertheless, applied behavior analysis is widely used in people with intellectual disabilities, and additional benefits seem to be gained from cognitive-behavioral, psychosocial, psychodynamic, and expressive therapies (e.g., Benson & Havercamp, 2007). Consensus guidelines are also available for the use of psychotropic medications in people with intellectual disabilities (Szymanski & King, 1999). In addition to research on reducing distressful symptoms, interventions are also now being used in the general population that promote positive states, including positive emotions, engagement, and meaning (Seligman, Rashid, & Parks, 2006). Techniques that enhance these states are effective in treating depression, and may hold particular promise for persons with intellectual disabilities (Dykens, 2006). Although encouraging, researchers have yet to weave together these separate strands to create integrative, evidence-based treatments similar to those seen in mainstream psychiatry or psychology.

The future of research in intellectual disabilities

From this quick tour of past and future work in intellectual disabilities, one can see major advances and major gaps. Advances include work on behavioral phenotypes, the movement over the past two decades to go beyond studying children with intellectual disabilities as a single group, but to focus instead on children with specific genetic syndromes. Such work, in turn, has pushed forward the identification of specific gene–brain–behavior connections. Yet at the same time, we know relatively little about many areas. We know little about basic demographic issues among children with intellectual disabilities (or with a specific syndrome) and their families, which aspects of the child influence others, and the effects of aging and gender. Our knowledge of interventions is similarly rudimentary.

Intellectual disability research is thus at an important moment. Over the past 50 years, a small group of researchers has advanced our knowledge of these children and their families. Consistent with Tizard’s (1966) comments over 40 years ago, the research field of intellectual disabilities remains small and less fashionable than other areas of child psychiatry. Still, bolstered by the discipline-specific issues that such children present to workers in many diverse fields, our sense is that intellectual disability work will slowly expand over the next few decades. Although it is probably best to avoid invoking (again) the Cinderella metaphor, we do predict that future research will increase our...
knowledge of children with intellectual disabilities far beyond anything envisioned right now, the occasion of JCPP’s 50th birthday celebration.

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Key points:

- Within the larger field of child psychiatry, intellectual disabilities (ID) has historically played a small but steady role.
- Recent interest has grown due to the propensity of several genetic ID syndromes to show specific maladaptive behaviors and psychiatric conditions.
- Future work will elucidate the ties among genes, brain, and behavior, as well as the specific workings of environmental effects and gene–environment interactions.
- We need to know much more about how children’s maladaptive behaviors, health problems, appearance, and the timing–certainty of diagnoses all influence others.
- We need greater understandings of basic demographic characteristics and public-health needs of individuals with ID and their families, the effects of aging and of gender, as well as how to best translate research-based findings into effective interventions and supports.

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