

A New Generation of Research in Intellectual Disabilities:
Charting the Course

A Special Olympics Working Conference

Miami, FL

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Special Olympics, the world's largest organization for people with intellectual disabilities, has been committed to research and program evaluation to guide its understanding of both the needs of its constituents and the issues confronting individuals with intellectual disabilities around the world. With the power of empirical research Special Olympics has successfully been able to leverage their global influence to bring issues confronting people with intellectual disabilities to the forefront and charge international policy leaders with the responsibility for improving quality of services to their citizens with intellectual disabilities.

In 1999, at the Summer World Games in North Carolina, Special Olympics convened a meeting with leading scholars, at which it reaffirmed its commitment to research of relevance to the community of people with intellectual disabilities and their families. As a result of this meeting several key research areas were identified for study, including the influence of Special Olympics programming on athlete health and well-being and its impact on the family. Since this meeting, Special Olympics has been building its research networks through the initiation of the Global Collaborating Center at the University of Massachusetts Boston and the Regional Collaborating Center at Wenzhou Medical University in Wenzhou China. These Collaborating Centers have carried out major national and international studies related to public attitudes, health and medical practices.

The research community has also demonstrated an interest in Special Olympics. Since the late 1970's, more than 70 articles, dissertations, and reports focused on Special Olympics programs or its constituents have been published. Much of the research involving Special Olympics has focused on medical issues facing individuals with intellectual disabilities and, perhaps not surprisingly, on the effects of physical activity on participants (Escamilla, Lowry, Osbahr, & Speer, 2001; Harris, Rosenberg, Jangda, O'Brien, & Gallagher, 2003; Pastorfield, Pueschael, Lenihan, Medlen, Wagner, & Corbin, 2003; Roswal, Roswal, & Dunleavy, 1984; Woodhouse, Adler, & Duignan, 2003). Other studies have focused on athletes' motivation (Harada & Siperstein, 2008; Mikelkeviciute, Sajute, & Paulauskaite, 2005; Shapiro, 2003) and the physiological benefits gained from participation in Special Olympics (Balic, Mateos, & Blasco, 2000; Wright & Cowden, 1986). Researchers have also included Special Olympics

athletes in studies that explored self-concept and the social competence of individuals with intellectual disabilities (Dykens & Cohen, 1996; Gibbons & Bushakara, 1989; Weiss, Diamond, Demark, & Lovald, 2003; Wickiser, 2002). Some studies have looked beyond the athletes to explore the impact of Special Olympics on the family (Weiss & Diamond, 2005; Megginson, Nakamura, & Furst, 1997). Others have addressed the public's attitudes toward individuals with intellectual disabilities (Siperstein, Norins, Corbin, & Shriver, 2003; Siperstein, Parker, Norins, Widaman & Corbin, 2007; Storey, Stern, & Parker, 1990; Burns, Storey, & Certo, 1999) as well as the intersect between Special Olympics and community/school inclusion (Polloway & Smith, 1978; Orelove, Wehman, & Wood, 1982; Wilhite & Kleiber, 1992).

Clearly, Special Olympics and the research community have laid the groundwork for a mutually beneficial relationship. To date, however, those collaborations that have occurred have taken place sporadically and outside of an established infrastructure. To that end, Special Olympics International and the Global Collaborating Center at UMass Boston convened a working conference, "A New Generation of Research in Intellectual Disabilities: Charting the Course" with support from the Center for Disease Control (CDC), in Miami, December 6-7, 2007. The idea for the conference was rooted in the CDC's desire to raise awareness of the need for more research, program development, and program evaluation in the area of intellectual disabilities. Special Olympics capitalized on this as a valuable opportunity to acquire a greater understanding and appreciation for current research in the field and communicate its desire and capacity to adopt a more active role in the research community. The goals of the conference were:

1. To provide the research community with an awareness of the interests and commitment of Special Olympics to support research in the field of intellectual disabilities.
2. To chart a roadmap for future research in the field of intellectual disabilities.
3. To facilitate a dialogue between Special Olympics and the research community to determine how to enter into collaboration and identify collaborative initiatives.

Conference Development

To reach the above goals, we invited 25 national and international leaders in the field of intellectual disability research. We recognized that this small group of scholars did not represent the total breadth and depth of the field; nonetheless they represented a wide range of interests (e.g. health, education, and employment) and included researchers who had previously partnered with Special Olympics. Consideration and care were taken to include participants who were well situated to appreciate the history of the field, understand the current state of research, and offer guidance for future research.

During the planning phase, there was some discussion about whether or not to include stakeholders and advocates as conference participants. While we recognize that their voices are crucial in establishing a research agenda on intellectual disability, we made a difficult decision to limit this initial meeting to the research community. In recent years there have been several major conferences that have brought the research, advocacy, and service communities together in an effort to bridge the gap between research and practice (e.g., *Keeping the Promises*, Lakin & Turnbull, 2005). To ensure a connection between these past and present discussions of the field's research agenda we made certain that scholars were invited who had participated in these important discussions. We also reviewed the proceedings from previous conferences to ensure that we could build on, but not duplicate, that which had come before.

Finally, an underlying objective of the conference was to foster the next generation of researchers. Therefore, each invited leader was asked to invite a graduate student, a post-doctoral fellow, or an early career faculty member. These young scholars were included to emphasize the importance of research in intellectual disabilities as well as to help ensure the field's future. It is this group of promising researchers who are best situated to breathe new life into a field that many worry has lost its vitality. Project officers from the major federal agencies (NICHD, IES, CDC) were also invited to participate in discussions about future directions for the field. [See Appendix A for a complete list of participants].

With input from the invited scholars, we decided to structure the conference around developmental life stages, rather than around specific topic areas (e.g. health, employment, community integration). There was general agreement that taking a developmental approach had the potential to encourage greater dialogue across topic areas. Moreover, we believed that a

developmental approach would engender discussions about the ways in which knowledge of one life stage facilitates a deeper understanding of outcomes at a subsequent life stage.

The conference was structured to create a balance between discussions of the current state of research in the field and areas and opportunities for future research, with particular attention to those areas that lend themselves to collaboration with Special Olympics. For the first day, participants were asked to revisit past research in intellectual disabilities, describe the present field, and identify goals for the future. On the second day, the focus was on areas of research that deserve greater attention and how this work can be facilitated in the future through partnerships with Special Olympics. Throughout the conference, there were opportunities to reacquaint scholars with Special Olympics and its commitment to research, as well as to explore Special Olympics' capacity for engaging in partnerships with the research community. [See Appendix B for a copy of the conference agenda].

Proceedings

In the following sections, we provide a synthesis of the conference proceedings and discuss the themes and ideas that emerged over the two days. First, we provide highlights of the historical retrospective provided by the conference keynote speaker, Dr. Don MacMillan, with commentary from Dr. Steve Forness; we also include highlights of Dr. Timothy Shriver's presentation on the "new" Special Olympics. Second, we discuss the broad themes that emerged on the current state of research. Third, we address specifically the notion of partnership with Special Olympics, by articulating those research questions that participants identified as most appropriately addressed through collaboration. Fourth, we highlight the unique opportunities for researchers that can result from collaboration with Special Olympics. Finally, we discuss Special Olympics' role in creating partnerships, specifically, by providing a number of concrete action steps that Special Olympics must take to build the capacity needed to assume an active role in the intellectual disability research community.

Retrospective

Dr. Donald MacMillan and Dr. Steve Forness presented a retrospective look at the field of intellectual disability research, providing a backdrop for the discussions to follow. This

historical perspective provided an incentive for developing new ways to think about future work in the field, and offered a rationale for partnering with Special Olympics to revitalize the field.

Opening the conference, Dr. MacMillan called upon participants to remember when research on intellectual disability was at its zenith during the 1960's and 1970's. He proceeded to identify the many disparate but interconnected reasons why research flourished during this period of time. A key reason was that a number of influential leaders were able to successfully educate policy makers that intellectual disability was a major social problem confronting the country. Their case was made with a report demonstrating that the prevalence of children served in public schools with intellectual disability had increased by 400% from 1948-1966. Commonly accepted prevalence estimates at the time estimated approximately 3% of the total population having mental retardation (actually reflecting the percent of a birth cohort that would ever be labeled as mentally retarded at some time in his/her life). This sharp increase was due in part to the shifting emphasis placed on mild intellectual disability that began in the 1960's and its connection to poverty, social class, etc., thus demonstrating that intellectual disability was not only a medical problem, but a social problem as well.

In response to these efforts to bring attention to intellectual disability, major federal funding was allocated for research, attracting scholars from a wide range of disciplines, including anthropology, sociology, medicine, education, psychology. These new researchers strived to establish not just their own niche of research in intellectual disability, but were also committed to developing a broader research agenda. As a field, answers to emerging questions were being sought through empirical and exploratory research, rather than rhetoric. The focus was on the core deficits of intellectual disability – memory, cognition, problem-solving – and this eventually widened to include others aspects of functioning including social and interpersonal difficulties. The research that was conducted during this time illustrated the complexity of the issues facing individuals with intellectual disability, issues for which there were no easy answers.

Following his retrospective, Dr. MacMillan posed three challenges for us to reflect on in thinking about the future of the field. First, he challenged the group to consider how inclusive or exclusive the field should be in terms of defining intellectual disability. Since the 1960's, there has been a significant transition in how intellectual disability is defined and serviced. In the past, children with IQ's of below 85 were described as having an intellectual disability. Today

however, the cutoff score has been lowered to 70, resulting in cases in which children who previously would have been defined as having mild or borderline intellectual disability are either unlabeled or receive a learning disability or autism label. This makes research in “intellectual disability” challenging, in part because these changes in definition have impacted how the public perceives the importance of intellectual disability as a social problem. Dr. Forness, in his presentation, suggested that the field begin to embrace dually diagnosed children, and that we consider the possibility of four constituency groups of children with intellectual disability: children with severe intellectual disabilities, children with mild intellectual disabilities who are in special classes, children with mild intellectual disabilities who are in inclusive environments, and children with mild intellectual disabilities who are classified as having a learning disability (and subsequently labeled as “non-responders” to intervention).

Second, Dr. MacMillan charged us with the task of attracting the best minds in a variety of disciplines and professions to address the causes and behavioral characteristics of intellectual disability, as well as the interventions that maximize the quality of life of individuals with intellectual disability. He noted, however, that the field is challenged with developing the next generation of researchers who are going to continue work in the field. Finally, Dr. MacMillan questioned whether we want empirical evidence or rhetoric to guide our interpretations of definition, causation and treatment. He suggested that there have been decreases in funding for research in intellectual disability and that they were, in part, due to the increased rhetoric that has overshadowed empiricism.

Following the retrospectives of Dr. MacMillan and Dr. Forness, Dr. Timothy Shriver, Chairman of the Board of Special Olympics International, described how Special Olympics has evolved from a “nice” sport organization for people with Down Syndrome to a global “movement” promoting the value of persons with intellectual disabilities. While much of the field is polarized around ideas of whether to include or segregate (social isolation vs. support) and whether to label (stigma vs. protection), Special Olympics chooses to see apparent vulnerabilities of persons with intellectual disabilities as “windows into strengths”, and uses situations of social isolation as “opportunities for social change.”

Dr. Shriver indicated that an integral part to the new Special Olympics movement is forging partnerships to carry out rigorous research, and he suggested several areas (“vectors”) of convergence between Special Olympics and the “field of inquiry.” Describing the new Special

Olympics initiatives, such as Healthy Athletes, Athlete Leadership Program, Young Athletes, and Unified Sports, Dr. Shriver suggested that these programs could speak to the potential role of sport as a change agent in health, social and adaptive behaviors, educational and employment outcomes, and positive family perceptions. Dr. Shriver also encouraged the shift from research situated within a deficit model to a focus on the absolute value of people with intellectual disabilities. Similar to the challenges presented by Dr. MacMillan and Dr. Forness, Dr. Shriver called for an “aggressive and engaged research agenda that informs public policy in just the way it did in the 1960s, combined with strong advocacy from stakeholders like parents and concerned citizens.” He suggested that the field should be informed by a philosophical position that promotes value and meaningful living, transforming these ideas into empirical research “that can be a counterweight to the long history of deficit and deficit oriented research.”

Dr. Shriver ended with several important questions to frame the remainder of the working conference, focusing on how researchers and Special Olympics can work together.

- What are the key research questions that can serve as the interface points between Special Olympics and the field?
- How can Special Olympics capitalize on existing strengths to advance the field?
- What questions are realistic to tackle now, through collaborations with individuals in the room today?
- How can we design a research platform that lifts the field as well as our movement?
- What questions remain?
- How can Special Olympics support the field in answering these questions?
- How can the field support Special Olympics?

Research Themes

As a core group of scientists in the field of intellectual disability research, participants agreed on the importance of adopting a developmental perspective when engaging in intellectual disability research. We recognized the possibility that individuals with intellectual disabilities may experience unique, or atypical, developmental trajectories and acknowledged that the needs of these individuals and their families change over the life course. With this recognition, however, we also concurred on a significant challenge to the research community that cuts across developmental stages, specifically, the challenge of moving from research to practice. There

were also several overarching research themes that appeared to be consistent across the lifespan, and that emerged from the proceedings of the four panel presentations. Those themes were: (1) the challenge of moving from research to practice; (2) the importance of considering context / environments in our research; (3) the centrality of participation for developmental success; and (4) health.

1) The challenge of moving from research to practice

There was general agreement that while we know a good deal about the populations we study and we are able to design effective interventions in controlled settings, we are consistently challenged to translate this knowledge (and these carefully designed interventions) into useful, feasible practice. This was frequently referred to as the challenge of “scaling up.” It appears to be a common frustration in the research field that we are challenged to affect broad impact. This was expressed in a number of different ways.

“We already know a lot about how to educate and support individuals with ID, but we don’t use this information very well” (Rob Horner).

“I have more confidence in the science of intervention research than in the science of implementation” (David Mank)

“I think a challenge is going to be moving from efficacy studies to effectiveness studies where we scale up and examine features, elements that it takes to actually scale up and deliver.” (Sam Odom)

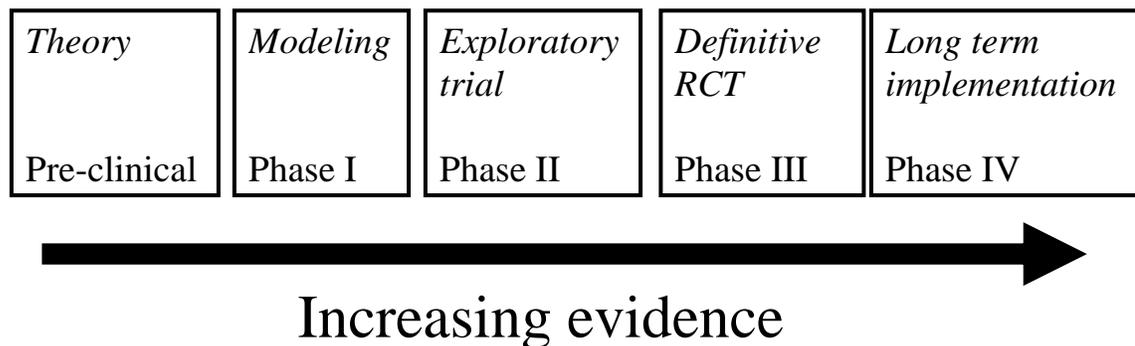
Many of the specific challenges were discussed:

- We need to create and evaluate interventions in response to the developing individual and family.
 - What specific developmental tasks do individuals need to accomplish at each life stage and what are their consequences for successful future outcomes?
 - How do the needs of families change over time and are there critical developmental periods in the adjustment of families?
- We need to better assess the short- and long-term effects of environmental differences and differential treatments.

- We need to identify clear goals and outcomes for interventions so that we can develop precise (valid and reliable) measurement tools.
 - How can we harness recent technological advances to improve the way we measure behaviors and environments?
- We need to re-evaluate our research designs with regard to unit of analysis when taking interventions to scale. A necessity of scaling up is broadening the unit of analysis (for example, from student to school, or child to EI program).
- We need a better understanding of how environments (e.g., families, schools, social, cultural) impact the effectiveness of interventions. We need to define critical context variables that are necessary to implement interventions successfully. For example
 - What is the impact of the changing family demographic (e.g., more mothers in the workforce) on naturalistic early childhood interventions?
 - How do the systems (organizational, financial, political) that surround and support our educational and service delivery practices impact our ability to deliver effective interventions?
- We need to identify variables that are critical in producing sustained effects.
 - Are the variables that are key to implementation and to the production of initial effects the same variables that are necessary to sustain effects (and programs) over time?
- We need to consider the impact of changing definitions, diagnoses, and classifications of intellectual disability on our research.
 - How does our shifting conceptualization of intellectual disability impact the development of new interventions and the sustainability of existing programs?
- We need to determine the appropriate function and form of randomized control trials (RCTs) in the scope of our work.
 - How do we reconcile the current political/funding emphasis on RCT research with our scientific, practical, and ethical objectives?

As evidenced by the list of challenges and questions presented above, there was a general consensus that our methodologies have not been effective in helping us translate our research into effective practice. In his summation of the first day’s proceedings, Dr. Richard Hastings presented the UK Medical Research Council’s (MRC) model for developing and evaluating evidence for complex interventions, a tool to help us evaluate our progress in this area (Figure 1). This model outlined five stages that encompass the range of scientific work necessary to implement a successful long term intervention: (1) developing theoretical foundations at the preliminary (or Pre-clinical) phase; (2) designing effective models of intervention (Phase I); (3) fine-tuning these models through exploratory testing (Phase II); (4) conducting definitive testing through RCT (Phase III), and finally (5) implementing long-term interventions (Phase IV). There was general agreement that this was a useful model for thinking about the different levels of research that are essential for developing interventions, evaluating them through the use of RCT’s, and taking them to scale, but that there are few good examples of effective research design at the final phase.

Figure 1. The UK Medical Research Council model for developing and evaluating evidence for complex interventions



2) The importance of contexts and environments

Many participants discussed the importance of contexts and environments in intellectual disability research. While we, as a field, clearly recognize that all individuals develop within multiple transactional contexts – family, schools, communities, cultural and political contexts – we are challenged to capture the full impact of these contexts in our research designs. This was

discussed as part of the challenge of scaling up, but it must also be considered as an issue in its own right. In our efforts to better understand the predictors of a range of developmental outcomes (and the effectiveness of interventions), we need to pay closer attention to the potential impact of environments. We must also be aware of the fluidity of context – environments change constantly – and work to account for this fluidity in our research designs. Thus, we are challenged to, first pin down these shifting contexts, and then consider their full impact on the development of individuals with intellectual disabilities. Three specific contexts that may be of particular importance for individuals with intellectual disabilities are family, peer groups, and school.

Families. Families play a very important role in the lives of individuals with intellectual disabilities throughout the lifespan. They are the primary source of continuity from birth through youth and beyond (Ann Kaiser). Several panelists also drew our attention to the important role that siblings play in the family, especially as the family ages.

- We recognize that while individuals with intellectual disabilities have multiple unique needs that shift over time, so do their families. We need to better understand these families in order to offer them appropriate (effective) services and ongoing support.
- In order to accurately measure the effects that families can have as mediators of development, we need to consider a range of family variables in our research designs, such as demographics, stress, and the value that families place on service delivery.
- We need to design interventions and services that facilitate the transition to independence for adolescents and emerging adults with intellectual disabilities, yet still promote and maintain strong familial bonds, particularly with siblings (considering the roles they play throughout the lifespan). This remains an important issue throughout adulthood.
- We need to develop a knowledge base around how to support families during adolescence and through the important time of transition to adulthood. We also need to translate available research into interventions targeted to support families during these life stages.

Peer groups. There was general consensus among the participants that social relationships with peers are important for normative development within and across developmental stages. Forming peer relationships is viewed as an important developmental task

during childhood and adolescence. Its successful mastery provides the foundation for future outcomes, especially in the transition to adulthood. However, there was also agreement that meaningful friendships and peer relationships are often lacking in the lives of people with intellectual disabilities.

- We need to continue to acknowledge the importance of friendships and meaningful peer relationships as part of the normative human experience, and establish this in our research as a critical developmental outcome and goal of intervention.
- We need to recognize and acknowledge the importance of close relationships throughout the course of adulthood, particularly intimate relationships.
- We need to develop a better understanding of how to encourage and promote the formation of friendships for people with intellectual disabilities.
 - What are the contexts out of which friendships can emerge?
 - What are the critical social skills that are necessary for friendship formation, and how can we design interventions that foster those skills in individuals with intellectual disabilities?

School. Clearly, education is an important consideration in the lives of children and youth with disabilities, and the education community was well-represented at the conference. Much of the discussion around designing effective, sustainable interventions and the challenges of implementation came out of discussions about education. School is recognized as a primary context for the development of social, academic, and life skills for children and youth with disabilities. The importance of school in preparing young people for adulthood was stressed repeatedly.

- We need to be aware of the ways in which the changing nature of intellectual disability impacts who is served by special education.
 - How can we document the changing definition of intellectual disability in the schools?
 - What are the relationships between the changes in who is served in special education and what is taught in special education?
- We need to broaden the way we think about educational programming, with regard to both what and how we teach students with intellectual disabilities.

- In what ways can we teach functional skills and healthy behaviors simultaneously with academic skills?
- How can we demonstrate that promoting functional skills and healthy behaviors also addresses academic standards?
- We need to focus more on education as preparation for the future and pay more attention to long-range goals and preparation for transition.
 - How can we design programs of transition education that will encourage youth with intellectual disabilities to think about their futures in a meaningful way?

3) Participation

There was general consensus that participation in a range of activities and environments is an essential part of the human experience and important for positive development. Certainly, we accept that typically developing children learn through participation. Is this also true or even especially true for children with intellectual disabilities, and can such a model be extended beyond childhood? Panelists spoke of participation in daily routines and in recreational activities, participation in the educational process, participation in communities, and civic participation.

“Participation is key to development” (Sam Odom)

“...when you have family, when you have friends, when you are part of a community, and when you belong to a society, then you are an ordinary human being. And maybe life’s as simple as that, giving people the opportunity to experience their humanity.” (Roy McConkey)

- We need to better understand how participation impacts developmental outcomes. Philosophically, we recognize the value of participation, but this recognition needs to be informed by rigorous scientific research.
- We need to better understand how to encourage and enhance participation in life activities.
 - How do environments (classrooms, communities, cultures) provide opportunities (or present challenges) for meaningful participation?

- How can we promote participation in leisure activities for individuals with intellectual disabilities (for example, including leisure under IEP goals and as a part of transition planning)?
- What supports are necessary to enable the integration of people with intellectual disabilities into community recreation programs as they transition out of school?
- How can we design interventions (at all life stages) that encourage and support active participation in multiple spheres?
- We need to address civic participation in terms of benefits to the individual and benefits to society.
 - How can we promote and facilitate participation in (and contribution to) community for individuals with intellectual disabilities?
 - What is needed to encourage community programs to integrate young people with intellectual disabilities?

4) Health

Health and well-being were critical themes that crossed all age groups. It was noted that obesity and lack of physical activity were problems for individuals with and without intellectual disabilities. There is very little comprehensive data on health for people with intellectual disabilities. People with intellectual disabilities and their families also face the problems of inconsistency of care and lack of transferable health care information. The family is usually the one source of medical history, but often has to repeat the information through every medical transition. There was also a consistent call to maintain a broad definition of health. Several panelists cited the WHO's three-pronged definition of health that encompasses physical health, mental health, and social well-being. This broad approach seemed to resonate with participants across disciplines.

- We need to explore the specific challenges that individuals with intellectual disabilities face around the transition from pediatric care.
- We need to focus more attention on the features of successful health-promoting environments and activities.

- What are the characteristics of inclusive healthcare environments for people with intellectual disabilities? (e.g., there is little or no inclusion of students with intellectual disabilities in school health programs, such as sex education)
- How do we promote and encourage self-management of health care?
- We need to continue to explore the extent of health disparities, with regard to both health conditions and access to care, for the population of people with intellectual disabilities.
- We need to better understand the mental health disparities that occur for individuals with intellectual disabilities and focus more on mental health needs of individuals with intellectual disabilities.
- We need to engage the mental health community to foster interest in the inclusion of individuals with intellectual disabilities in mental health research?
- We need to better understand the effects (and side effects) of medications on people with intellectual disabilities.
 - What is the interaction/relationship between medication and obesity in this population?
 - What is the interaction/relationship between medication and bone density (i.e., to what extent does medication/multiple medications decrease bone density?)
- We need to better understand the impacts of inconsistent/non-continuous health information on people with intellectual disabilities and their families
 - How does inconsistent/non-continuous health information contribute to stress in family/individual?

Specific Research Questions

A primary goal of the conference was to explore the areas of connection between Special Olympics and the research field and identify questions appropriately investigated through collaboration. A number of specific ideas for productive partnerships were generated, representing those areas that are of primary concern to both researchers and the Special Olympics organization. Participants took a largely pragmatic approach to this task, focusing on how research efforts could capitalize on existing Special Olympics programs. Current Special Olympics initiatives provide a useful point of departure; it was easy for participants to see the

connections between their work and Special Olympics by evoking the different Special Olympics programs, such as Unified Sports, Young Athletes, Healthy Athletes, the Athlete Leadership Program, and Special Olympics' school-based programming. During the conference, participants generated a number of questions that could be explored within each initiative. These questions are detailed in the following section, along with a brief description of each program.

Special Olympics Unified Sports is an inclusive program that brings together individuals with and without intellectual disabilities to play team sports. Unified teams have approximately equal numbers of athletes with intellectual disabilities and non-disabled partners. Divisioning, a method that helps to match skill levels of teams, helps to assure balanced competition and opportunities for all members of the team.

Questions related to Unified Sports:

- What are the physical, social, and educational benefits of participation in inclusive recreational programming for all participants (athletes with intellectual disabilities and non-disabled partners)? To what extent are these benefits sustained for both groups?
- What aspects of the Unified Sports program (e.g., intensity, content, duration) are most conducive to promoting the development of friendships between people with and without intellectual disabilities?
- For individuals with intellectual disabilities, what are the advantages to developing friendships with typically developing peers, and what are the advantages to developing friendships with peers with intellectual disabilities?
- How does family involvement in Unified Sports impact family perceptions/family dynamics at home? How does involvement in Unified Sports differ from traditional Special Olympics sports for families?
- What are the potential benefits of sibling involvement in sports with their brother/sister with an intellectual disability? For example, how does Unified Sports promote greater appreciation of siblings' abilities, qualities, etc.?

- What motivates partners (non-family members) to participate in Unified Sports? How does their Unified Sports experience meet their expectations? How do they change in their understanding or appreciation of athletes with intellectual disabilities?

Special Olympics Healthy Athletes is a program that provides comprehensive health screening to Special Olympics athletes to identify unmet health needs, provide preventive and educational services, make referrals for follow up care, train health professionals in the needs and treatment of people with intellectual disabilities, and do evaluation, research and policy development activities that support athlete health.

There was general agreement that the Healthy Athletes database could provide a much sought after longitudinal picture of the health status of individuals with intellectual disabilities. In addition, participants stressed the value of beginning this data collection process early, with young children (perhaps through the Young Athletes program), thus creating the opportunity for a comprehensive, ongoing health database. Again, such an effort was presented as mutually beneficial to the research community and Special Olympics. Not only could scientists use this database to better understand the changing health and care needs of individuals with intellectual disabilities, it would also provide constituents with a portable record of their health and wellness over a long period of time.

Questions related to Healthy Athletes:

- What are the salient factors of effective health promotion programs for individuals with intellectual disabilities (and their families?) at different life stages?
- How does current Healthy Athletes data compare with general population health data, both at the national and international levels?
- What are the benefits of continuity of health care information for all stakeholders (i.e., people with intellectual disabilities; their families and caregivers; medical professionals)?
- How can the Healthy Athletes prepare constituents to communicate their health status and health needs to medical professionals?

Special Olympics Young Athletes was designed to meet the physical / motor needs of younger children with intellectual disabilities. Traditionally, Special Olympics competitive sports have been open to those ages 8 and above; however, parents advocated for opportunities for their younger children (2 1/2 – 7 years). Young Athletes is a structured group program that entails elements of recreational skills development, socialization, motor coordination, confidence building, and language development.

Questions related to Young Athletes:

- How does participation in the Young Athletes program impact the overall development of young children with intellectual disabilities (e.g., motor skills, social skills, communication skills)?
- What aspects of the Young Athletes program (i.e, intensity, content, duration) are most salient for promoting positive developmental outcomes, in both the short- and long-term?
- What are the mechanisms (pathways) through which the Young Athletes program impacts development? (e.g., might the Young Athletes program exert an indirect impact on cognitive development through its impact on motor skills?)
- What are the impacts of involvement in Young Athletes on family interactions and family outcomes? What aspects of Young Athletes program are most salient for promoting family well-being and relationships?
- What are the impacts of the Young Athletes program on positive peer relationships? What characteristics of the program are most salient for promoting these social outcomes?

Special Olympics Athlete Leadership (ALPS) creates additional opportunities for athletes beyond training and competition. These opportunities include roles as coaches, officials, technical advisors, board members, spokespersons, and work group members. Training programs are available to athletes who wish to advance their leadership and communication skills.

Questions related to ALPS:

- How does the Athlete Leadership Program impact autonomy, leadership skills, and self-determination in its participants? What aspects of the program are most salient in promoting these outcomes?
- How does ALPS compare to other youth development programs (for young people without intellectual disabilities)?

Participants framed a number of questions that were not specific to any program in particular, but related to the goals and activities of Special Olympics more generally. Many of these questions related to the broad themes that emerged during the panel presentations and that were articulated in the previous section. To varying extents, the constructs of family, school, community, and health were embedded in all Special Olympics programming.

- What are the impacts of sports/recreation programs, such as Special Olympics, on classroom outcomes (e.g., social behavior / skills, self-esteem, attention)?
- Does engagement in recreational opportunities, such as Special Olympics, moderate stress associated with school transitions (i.e. out of school)?
- What is the value of recreational opportunities (like those provided by Special Olympics) for families of children and youth with intellectual disabilities? How do recreational opportunities promote greater family involvement/interaction? How does participation broaden families' social connections?
- How does participation in Special Olympics change parents' perceptions of their children with intellectual disabilities? In turn, how do these altered perceptions impact parent expectations related to work, independent living, and community involvement for their children?
- What are the barriers to accessing recreational opportunities such as Special Olympics for families of children with disabilities? (This question, in particular, focuses on those families who do not participate in recreational programming.)
- How does participation in Special Olympics enhance participation of athletes and their families in other normative life activities over the developmental course?

- What impact does participation in Special Olympics have on mental health? For example, how does involvement in Special Olympics impact the onset of mental health problems, such as social withdrawal and depression, among children and adolescents, particularly during periods of transition?

Opportunities created through collaboration with Special Olympics

For the research community, partnering with Special Olympics offers a range of benefits. Broadly, collaboration with Special Olympics can provide access to a very large international pool of people with intellectual disabilities of all ages and their families, as well as provide a valuable opportunity for global dissemination to a wide audience that includes policy makers and political leaders. The many opportunities that are opened up by partnering with Special Olympics are detailed below.

- Because of Special Olympics' global reach, partnership provides valuable opportunities for greater cross-cultural thinking and international collaboration.
- Because Special Olympics has many successful programs already in place, it offers naturally occurring laboratories to study the interface between individual, family, school, and community.
- Because Special Olympics provides programming for early childhood (age 3) through adulthood, it offers the opportunity for researchers to take a developmental approach and look at individuals and families across the lifespan. This opportunity may be particularly valuable for those with an interest in better understanding transitional periods, particularly the transition to adulthood (when we often lose track of people with intellectual disabilities, as they exit the educational system).
- Because Special Olympics' goal is to be a positive force in the lives of people with intellectual disabilities and their families, while capitalizing on their individual strengths and potential, a partnership facilitates research that is situated in positive conceptual models, outside of the traditional deficit model of intellectual disability.
- Because Special Olympics provides a variety of opportunities for family members to be involved, it invites researchers to look at the family within a systems perspective that allows

a better understanding of an individual's relationships with different family members (parents, siblings), as well as a better understanding of the family as a holistic system.

- Because Special Olympics focuses on sport and recreation across the lifespan, a partnership facilitates research interest in recreation as a critical component of a person's life and its impact on a range of developmental outcomes (e.g., health, psychological well-being, sense of self).
- Because Special Olympics has strong stakeholder involvement, it allows researchers the opportunity to engage stakeholders in the research process by inviting input and feedback at any and all stages (e.g., posing research questions, designing studies, interpreting findings, and disseminating results). Stakeholder participation offers researchers a valuable opportunity to broaden their understanding and appreciation of the applied value of their work and places social validity front and foremost.
- Because Special Olympics has powerful connections with policy makers and government leaders at the national and international levels, a successful partnership offers a large audience for disseminating research findings and expands the potential for transforming research into broad action/policy.

Building Special Olympics' Capacity for Partnerships

The conference succeeded in generating a great deal of excitement among participants about the potential for productive and mutually beneficial partnerships that can address a wide range of critical research questions. There was overwhelming agreement among the conference participants that as we move forward, Special Olympics must assume a leadership role in developing a strong, dynamic, and fluid research infrastructure that is able to support both existing and new partnerships. As the conference drew to a close, there was general consensus that Special Olympics must make a decision about **“the scale at which [they] want to be part of the research community, because there's a really wonderful opportunity here for leadership and shared participation and research”** (Kaiser). Participants who had previous experience working in direct partnership with Special Olympics articulated a number of next steps that Special Olympics must take to build their own capacity to expand partnerships with the research community. Two essential areas that must be addressed to develop this capacity are: the

need to build support at the program level and the need to create a viable data management system. Special Olympics can clearly communicate its commitment to research for the long-term by taking steps guided by the following suggestions to build a strong and solid infrastructure that supports partnerships,. **“The dependability of a collaborative relationship will be a huge incentive to researchers.”** (Ann Kaiser)

Creating support at the program level. Those who have partnered with Special Olympics in the past noted that local and state programs are key to the success of any collaboration. It is these individuals that provide access to Special Olympics athletes/constituents, and are often gatekeepers for accessing schools and/or other agencies involved with Special Olympics. Currently, state and local programs vary in their responsiveness to such collaboration. Some have voiced concern about their constituents being “used;” others have expressed worry that the burden of additional work for staff/volunteers will be too great. Conference participants agreed that a critical component to creating successful partnerships is communicating the value of research to the programs and building a sense of buy-in among the programs and their constituents. If local programs recognize the value of research and its applicability to programming they might be more willing to participate. Therefore, facilitating the relationship between programs (at the national, state, and local levels) and researchers, and raising an appreciation of the value of research is elemental to the success of research partnerships, especially those involving local programs. To accomplish this goal, a number of action steps were suggested:

- Special Olympics needs to clearly define and communicate its research priorities to program leaders throughout the US and world.
- Special Olympics needs to provide programs with the resources necessary to participate in research without compromising or diminishing their service to constituents.
- Special Olympics needs to designate a point of contact for research in both state and local offices.
 - Since local and state programs are the key to accessing constituents there needs to be a designated contact whose responsibility is to facilitate research initiatives (e.g. data collection, access to constituents, etc.)

- Special Olympics needs to collaborate with investigators to ensure that programs be seen as stakeholders in the development of research initiatives.
 - Communicate the relevance and meaningfulness of research to program development and operations.
 - Educate program staff about the research process.
 - Include program leaders in the development of research initiatives when possible.
- Special Olympics needs to create and implement a mechanism for disseminating research results to local and national programs in ways that are accessible and useful (e.g. research results that will inform current and future programming).

Building capacity through data management. There was consensus that Special Olympics must build their capacity to collect and manage information about their constituents and their programs. Conference participants expressed great interest in the current status of the Special Olympics' database, focusing on what data is collected and how it is gathered and stored. Participants pointed out that developing a more comprehensive database is a critical component for establishing successful research collaborations. It was pointed out that a strong database would give researchers access to primary and secondary data that might also be linked to other national datasets. Furthermore, conference participants pointed out that developing a comprehensive database would also be a great benefit to the organization and its local programs, as it could allow local, state and national program staff to track the changing nature of their constituents (age, impairment levels, educational/employment status, etc).

There was additional consensus among participants that Special Olympics needs to ensure fidelity and transparency in their data collection process so that the research community can determine the reliability, validity, and generalizability of the data. **“Understanding demographically who Special Olympians are ...[is] important both from the service perspective and from a research perspective; from a research perspective so we know who we are generalizing or can generalize to, but from service perspective, to know who is being left out”** [speaker].

Participants had many suggestions about the action steps that are necessary to improve upon the database with regard to the content, consistency, and accessibility of the data collected:

- Special Olympics needs to collaborate with researchers to establish guidelines about what generic (demographic) information should be collected across programs (to facilitate connection to larger datasets). Suggested variables included:
 - Athlete characteristics (diagnosis, impairment level, ethnicity, educational/employment/community setting)
 - Family characteristics (family composition, parent education level, number of siblings, etc.)
 - Program characteristics (athlete's participation in Special Olympics)
- Special Olympics needs to collaborate with researchers to establish guidelines about what program specific information should be collected that might be unique to each program's goals and objectives (for example, Healthy Athletes, ALPS, Young Athletes, etc.)
- Special Olympics needs to create a staffing infrastructure to handle inquiries from the research community.
 - How does Special Olympics respond to inquiries about the data they collect?
 - How does Special Olympics support researchers in the data collection process?
- Special Olympics needs to provide support to national and international programs to create capacity for computer-based data management, including both the technology and the training for using and maintaining the database.
- Special Olympics needs to address the ethical implications of making its databases available to researchers (both for program evaluation purposes, but more so for other research purposes).
- Special Olympics needs to create a mechanism for facilitating the IRB process such as including clearly defined questions for obtaining informed consent (for example, during the athlete registration process).

Above and beyond these areas of need, there was a general consensus among participants that Special Olympics can increase interest in the field by attracting researchers early on in their

scholarly careers. Special Olympics is well situated to be a training ground by providing valuable opportunities, such as offering funding for student and early career research. Participants also suggested that Special Olympics could develop internship programs to support secondary data analysis, collaboration in program evaluation efforts, and working with local programs to facilitate data collection. Taking an active mentoring role in the research community would strengthen the basis for a mutually beneficial relationship in which Special Olympics can help alter the trend of diminishing interest in research in intellectual disabilities while increasing their visibility in the community and expanding their support base. Furthermore, making the effort to support the next generation will cement Special Olympics' role in the research community for decades to come.

Reflections and Next Steps

The Miami Conference provided a valuable opportunity for Special Olympics and researchers who focus on issues of intellectual disability to get reacquainted and begin to explore the possibility of large-scale, extended, systematic collaboration. Certainly, one of the major outcomes of the Miami Conference was the overwhelming support and enthusiasm shown by the participants for developing a strong research partnership with Special Olympics. It was quite evident that participants view Special Olympics as a potentially valuable research partner, largely because of the size of its constituent base, its historical legacy, and its global presence. Perhaps even more important, Special Olympics and the research community share a common goal to improve the lives and well-being of persons with intellectual disabilities at each life stage.

The well-informed and high-spirited discourse that occurred in Miami demonstrated that the future holds great promise for the field of ID research. Our next steps will draw on the collective energy and wisdom of the conference participants. We have identified several senior scholars to bring together as a Leadership Team. One of the primary tasks of the Leadership Team will be to work with SO to identify feasible first steps for immediate action, with a particular focus on building SO's capacity for research partnerships. We are now poised to harness the momentum generated in Miami to develop a strategic plan for successful collaboration.

New Generation of Research in ID: Charting the Course
A Special Olympics Working Conference
December 6-7, 2007
Miami FL

THURSDAY DECEMBER 6, 2007

WATSON GENERAL SESSION ROOM – 2ND FLOOR

- 8:30 **Welcoming Remarks: Gary Siperstein and Steve Corbin**
- 8:45 **Keynote Presentation: Donald MacMillan**
Mental Retardation Over Five Decades: Lessons We Might Have Learned
- 9:15 **Commentary: Steve Forness**
Historical Trends and Interdisciplinary Issues
- 9:30 **Open discussion**
- 10:00 **Special Address: Timothy P. Shriver**
The New Special Olympics: Building a Foundation for Evidence-Based Practice
- 10:30 **BREAK**
- 10:45 **Panel 1: Infancy & Early Childhood**
(Don Bailey, Anne Kaiser, Sam Odom, Steve Warren)
- 11:45 **Panel 2: School-Age/Middle Childhood**
(Rob Horner, Gloria Krahn , Jim Mulick, Ed Polloway, Michael Wehmeyer)
- 12:45 **LUNCH - Bayview Terrace**
- 2:00 **Panel 3: Adolescents – Young Adulthood**
(Elisabeth Dykens, Laraine Glidden, Jim Patton, Marsha Seltzer)
- 3:00 **Panel 4: Middle Adulthood – Ageing**
(Henny Lantman, David Mank, Bill MacLean, Roy McConkey)
- 4:00 **Closing Remarks: Gary Siperstein and Steve Corbin**

FRIDAY DECEMBER 7, 2007

WATSON GENERAL SESSION ROOM – 2ND FLOOR

- 8:30 **Commentary on Day 1: Richard Hastings**
Synthesis and Analysis of Panels across the Lifespan
- 9:15 **An International Response: Patricia Noonan Walsh**
- 9:30 **Models of Collaboration with Special Olympics: A Roundtable Discussion**
(Coreen Harada, Elisabeth Dykens, Tamar Heller, Darcie Mersereau, Glenn Roswal)
- 10:15 **BREAK**
- 10:30 **Break-out Sessions of Working groups – 3rd Floor**
- **Infancy & Early Childhood (Lummus)**
 - **School Age & Middle Childhood (San Marco Island)**
 - **Adolescence & Young Adulthood (Biscayne Island)**
 - **Adulthood & Ageing (Sunset Island)**
- 12:30 **LUNCH - Bayview Terrace**
Dessert and Q&A with representatives from Tiina Urv (NICHD), Vince Campbell (CDC), and Jacquelyn Buckely (IES)
- 2:00 **Break-out Sessions – Working Groups continued**
- 3:00 **Reports from Working Groups: Priorities and Action Steps - Watson Room**
- 3:30 **Closing Remarks - Next Steps: Gary Siperstein and Steve Corbin**

This conference is supported by a cooperative agreement from the U.S. Centers for Disease Control & Prevention

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Conference Participants

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Dr. Vincent Campbell, Centers for Disease Control and Prevention

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