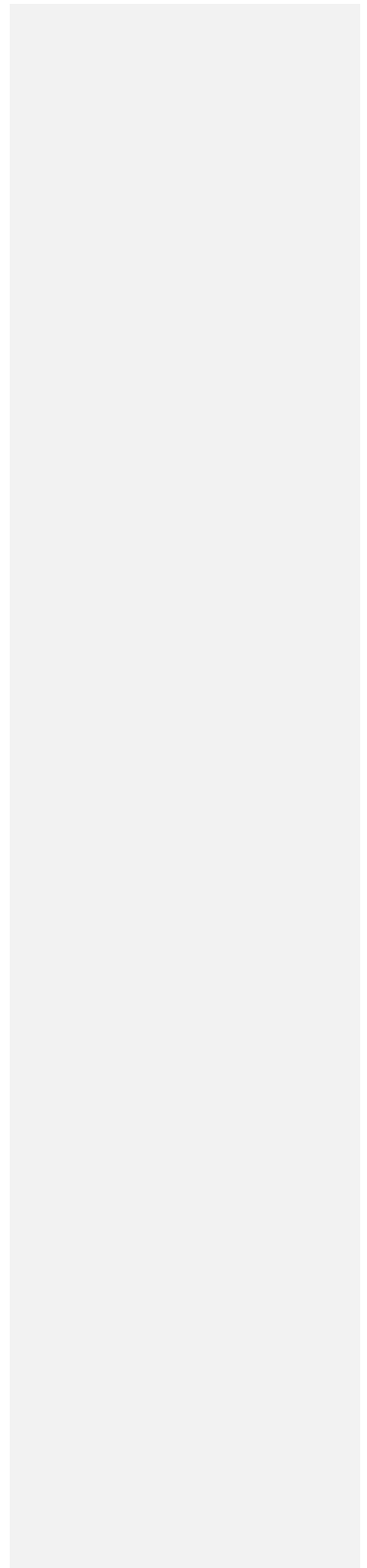


The Positive Contributions of Special Olympics to the Family

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Introduction

Special Olympics recognizes the value of families in their organization. Family members serve as coaches, officials, fund raisers, and chaperones. In fact, Special Olympics describes families as “the most powerful and valuable natural resource” they have. In turn, anecdotal evidence suggests that families also value Special Olympics, not just for the advantages it offers their children, but for the benefits it has to offer the whole family. Parents value Special Olympics as an opportunity to witness the competence of their sons and daughters with intellectual disabilities and also as a source of social support for themselves. Unfortunately, so far there has been little empirical evidence to support the family perspective.

Despite the lack of research focused specifically on families of Special Olympics athletes, there is a considerable body of research that has focused on the functioning of families of individuals with intellectual disabilities, in general. By and large, this research has been grounded in a deficit model that has assumed compromised outcomes for the individuals and challenges for their family members. Historically, researchers assumed psychological distress and poor adjustment for family members of children with intellectual disabilities (e.g., Farber, 1959, 1960; Jordan, 1962; Solnit & Stark, 1961). For example, early research suggested that parents experienced “chronic sorrow” over having a child with a disability (Olshansky, 1962). Recently, paralleling a burgeoning interest in methods and models of “positive psychology” (e.g., Seligman, 2000), scholars who focus on the study of disability in the family have begun to call for work that focuses on positive outcomes instead (Dykens, 2005; Helff & Glidden, 1998).

Contemporary researchers have begun to illuminate the positive experiences of parents of children with intellectual disabilities and identify the ways in which these families are thriving and even benefiting from having a child with a disability (e.g., Blacher & Baker, 2007; Stainton & Besser, 1998). For example, parents have reported a variety of positive transformations as a result of having a child with a disability, including personal growth, improved relationships both within and outside the family, and re-examination of personal values (Scorgie & Sobsey, 2000; Taunt & Hastings, 2002). Similar benefits have also been documented for siblings. Above and beyond the high levels of warmth that characterize their relationships with their brothers and sisters with intellectual disabilities (e.g., Kersh, 2007), siblings have also reported that having a brother or sister with an intellectual disability has helped them gain patience, tolerance, benevolence, and appreciation of health and family (e.g., Eisenberg et al., 1998; Van Riper, 2000). This emerging body of research that focuses on positive outcomes for individuals with intellectual disabilities and their families offers a more balanced, and thus an arguably more accurate, portrayal of this population.

In this study, we have continued to explore the positive perceptions and experiences of families of youth with intellectual disabilities by focusing on families of young people who are active participants in Special Olympics. Because Special Olympics values the personal strengths and individual competence of their athletes, while at the same time, acknowledging the importance of families, we believe that it provides an important context for an exploration of individuals with intellectual disabilities and their families that is grounded in principals of positive psychology.

While the positive impacts of participation in Special Olympics have been documented for athletes (e.g., Dykens & Cohen, 1996; Klein, Gilman, & Zigler, 1993; Siperstein, Harada, Parker, Hardman, & McGuire, 2005; Weiss, Diamond, Demark, & Lovald, 2003), the value for the family has been considered to a much lesser extent. In one notable exception, interviews with parents of young children participating in the Special Olympics Young Athletes Program indicated that families gained a variety of benefits from their involvement, including improved family dynamics, heightened awareness of their child's capabilities, and opportunities to connect with other families (Favazza & Siperstein, 2006). In another recent study, Weiss (2008) suggested that involvement in Special Olympics may serve as an important source of social support for mothers of adults with intellectual disabilities.

Therefore, the goal of this study was to explore the ways in which involvement in Special Olympics benefits both individual family members and the family system. We wanted to document the positive impacts that Special Olympics has on the family, such as helping to shape family members' perceptions of the athlete, strengthening family relationships, and promoting social support networks. We believed that involvement in Special Olympics would impact the family both directly, through the opportunities it provides family members to engage and interact with each other and with other families; and indirectly, through its impact on the athlete and on family members' perceptions of the athlete. In summary, there were three overarching research questions that guided this investigation about Special Olympics athletes and their families:

- 1) How do families perceive their adolescent and adult children with intellectual disabilities, and how does participation in Special Olympics impact their perceptions?

- 2) How do families believe that participation in Special Olympics benefits their children with intellectual disabilities?
- 3) How are family members involved in Special Olympics, and how do they benefit from this involvement?

Methodology

Participants

The participants in this study were randomly selected from active Special Olympics participant rosters in four states (Connecticut, Florida, Michigan, and Utah). To be eligible to participate in the study, athletes needed to have participated in Special Olympics within the last year and be living in the family home at the time of the study. The final sample for this study included 120 families of adolescent and young adult Special Olympics athletes. Within these 120 families, 104 mothers, 49 fathers, 38 siblings, and 49 athletes were interviewed. The athletes ranged in age from 13 to 30 which provided the opportunity to consider families of young athletes who are still in school as well as those who have made the transition to post-school life. A total of 72 athletes (60%) were still in school. Of those who had left school, 45% were competitively employed, 8% were working in sheltered workshops and, 8% were engaged in non-paid volunteer work experiences. Table 1 provides more detailed information about the athletes in the study and their families.

Athletes' length of involvement in Special Olympics ranged from 1 to 22 years, with a mean of 7 years. About half of the athletes (53%) originally became involved in Special Olympics through school, with about two-thirds (66%) getting involved before the age of 13. While athletes competed in a variety of sports, the most frequently named were bowling (68%), track and field (56%), and basketball (47%). Athletes spent an

average of 3 hours per week involved in Special Olympics related activities. On average, they were involved in four different Special Olympics sports. Almost all of the athletes (90%) had competed at the regional or state level. Two athletes in the study had competed at the national level, and two had competed in a World Games event.

Table 1. Description of Athletes (n= 120)

	N	Percentage	Range	Mean (SD)
Child characteristics				
Gender (male)	71	59%		
Age			13-30	19.45 (4.2)
In school	72	60%		
Type of disability (primary)				
Down syndrome	32	27%		
Intellectual disabilities (other genetic etiology)	12	10%		
Intellectual disabilities (non-genetic; includes traumatic brain injury)	32	27%		
Autism	11	9%		
Cerebral palsy	10	8%		
Multiple disabilities	3	3%		
Other	19	16%		
Family characteristics				
Race				
White	97	81%		
Black	5	4%		
Other	12	10%		
Unreported	6	5%		
Household income				
< \$25K	14	12%		
\$25 – \$50K	16	13%		
\$50 – \$75K	25	21%		
> \$75K	38	32%		
Unreported	37	23%		

Interviews

All data were collected through telephone interviews that contained both open- and close-ended questions. Interviews with parents and siblings included questions about the following: 1) family members' perceptions of the athlete; 2) the perceived impact that Special Olympics has on the athlete; 3) family members' involvement in, and experiences of, Special Olympics; and 4) the impact of Special Olympics on the family. (All interview protocols are included in Appendices C-F .) One parent in each family, generally the parent with whom initial contact was made, was designated as the primary parent. This parent was also asked to provide information on the athlete's involvement in Special Olympics, present educational and employment status, and general information about the family (e.g., household composition, race/ethnicity, etc.). Interviews with the athletes addressed their Special Olympics experiences, as well as their experiences of having their family watch them compete.

Procedures

Each of the four participating state Special Olympics Programs generated a random list of active athletes from its database. Each of these athletes and their family was sent a letter that described the study and explained that they had been randomly selected to participate and could expect a telephone call from a member of the project staff (see Appendix A).

When phone contact with a family member was established, trained interviewers followed a scripted protocol in which they introduced themselves and explained the purpose of the survey. Participants were informed that their responses were voluntary and confidential. A brief series of screening questions (see Appendix B) was asked

during this initial telephone call to find out if the athlete and family met criteria for participation. Specifically, interviewers established that the athlete was no older than 30, lived at home, and had been active in Special Olympics during the past year. If the parent expressed interest in participating in the study and the athlete and family met criteria for involvement, interviewers asked if they could proceed with the interview or if the parent would like to schedule a different time for the phone interview.

Interviews with the primary parent took approximately 30 minutes. At the conclusion of the primary parent call, interviewers asked if it would be possible to speak with other family members, specifically, the other parent (when appropriate), a sibling (when appropriate), and the athlete. Again, callbacks were scheduled when necessary. Secondary parent and sibling interviews lasted about 15 minutes. Athlete interviews were brief, generally lasting approximately 5 minutes. Interviews were audio-taped with the permission of the participating family members.

Results

Question 1: How Do Families Perceive Their Children with Intellectual Disabilities, and How Does Participation in Special Olympics Impact Their Perceptions?

Families' perceptions of their children with intellectual disabilities. Family members overwhelmingly expressed very positive views of their children with intellectual disabilities. Mothers and fathers easily ascribed a range of strengths to their sons and daughters, describing them as outgoing, friendly, kind, capable, and hard-working. Just like any parents, these mothers and fathers were proud of their children's positive character traits, such as their sense of humor, compassion, or affability, as well

as in their individual achievements (e.g., graduating from high school, singing a solo in the church choir, or taking first place in a sporting event).

Parents also reflected on the challenges of raising a child with a disability. However, even when discussing the challenges that both they and their children had faced, parents continued to express great warmth and pride and often framed the challenge within a positive perspective. For example, some parents reflected on accomplishments that might not seem significant to the parents of a typically developing adolescent or young adult, like reading a book or riding a bike, but for a parent of a child with an intellectual disability, these accomplishments exceeded their expectations. Even small accomplishments are significant to families, and in fact, “just the little gains” were a source of pride. One father of a 19-year-old young woman said, “My gosh, I’m proud she even survived. She wasn’t supposed to.” What should be noted is that regardless of their child’s functional level, parents expressed great pride and described a variety of assets.

Parents also recognized that others may not view their children the same way that they do. When asked what they would like others to know about their sons and daughters with intellectual disabilities, many parents (72%) further reflected on their children’s positive characteristics and strengths. These parents often said that they just wanted people to know that their adolescent or young adult child was “a great kid” or “a kind, caring person.” These responses reaffirmed parents’ positive perceptions of their children, but they also indicated that parents acknowledged that others often fail to see their children’s strengths and abilities. In fact, some parents (24%) brought up societal attitudes. These parents talked about societal misunderstandings of disability, and

regretted that others frequently underestimated their children's competence. One parent told us, "Unfortunately, kids like her aren't given much of a chance, but once they get a chance to prove what they are or what they can be, it amazes some people." Similarly, a number of parents (20%) expressed the sentiment that they would like others to know "that besides his disability, he's just like you and me." They told us that others often fail to acknowledge the humanity of their children and have a difficult time looking beyond the disability to recognize the many ways that they are, in fact, quite typical. As another parent expressed, "He has dreams, and he thinks. I mean, he has thoughts and hopes just like everybody else." In summary, parents expressed regret that others generally did not share their positive views of their children.

The impact of Special Olympics on family members perceptions. Parents and siblings discussed at great length the ways in which Special Olympics had contributed to their positive perceptions. Parents frequently mentioned the pride that they experienced when watching their sons and daughters train and compete. One parent referred to it as "the usual stuff that any parent gets any time their kid does well." Many of the parents commented that they were impressed, and often surprised, by their child's athletic ability, by their level of effort, their competitive nature, and by their demonstrations of sportsmanship. It was clear that outside of Special Olympics, parents had few opportunities to see their children with intellectual disabilities demonstrate these competencies and assets, because "without Special Olympics, they wouldn't have the opportunity to compete." While parents often get the chance to be proud of and cheer for their typically developing children, they may, unfortunately, have less opportunity to publicly express the pride they feel for their children with intellectual disabilities. The

following quote, from a mother of a 27-year-old young man illustrates this idea, and illuminates how her son with intellectual disabilities, in some ways, is no different than her other sons. She said that she attends Special Olympics events to...

...see my baby compete -- see my baby out there doing his best. And he's competing. He's actually up there striving to be the best, and that just makes me feel good -- real good. I'll be cheering and hollering like a cheerleader. I've got the biggest mouth out there...I think he thinks it's embarrassing. But all my kids do. I get excited. I get involved. So, I get real excited. Well, I'm sure they wouldn't have it any other way.

Similar sentiments were expressed by siblings. Half of the siblings (52%) interviewed said that attending Special Olympics events gave them the opportunity to witness and be proud of their brothers' and sisters' abilities and accomplishments. For example, one sibling talked about his experiences watching his brother compete this way, "He is not holding anyone's hand; he is doing what he learned by himself. It makes me happy." Similarly, many siblings (59%) said that attending Special Olympics events gave them the chance to support and encourage their brothers and sisters in their accomplishments ("I go because I want to support my sister through everything").

Beyond giving family members the opportunity to cheer and appreciate their athletes' abilities and accomplishments, approximately two-thirds of parents (65%) felt that participation in Special Olympics had elevated their expectations of their sons and daughters. As parents described how their expectations had been positively impacted, one theme that emerged was that Special Olympics had made them more aware of the extent of their sons' and daughters' capabilities and potential. As one parent explained it, "when you realize all their potential and abilities within the Special Olympics, you realize that they can succeed in [other] things." This suggests that parents, as well as the general public, may underestimate their children with intellectual disabilities. When

people with intellectual disabilities are challenged and given the opportunity to succeed in a variety of venues, they often demonstrate to others that they are highly capable. One mother told a story about watching her son, a figure skater, learn a complicated jump:

I thought, “Oh, no, no, no, no, no. That guy is going to kill himself if he does that.” ... He started around the circle, and I said, “I can’t watch. I cannot watch.” ... He leaped into the sky and spun around ... and then he came down, and he almost crashed, but he didn’t. He messed up, but he didn’t crash. And he was laughing and laughing and laughing. Me – I was shaking all over... I was thinking we were going to have to head to the emergency room. Oh, yes, he’s done a lot of things that I didn’t know that he could do. I didn’t think that he would be able to do it – or I’d think it was too far, or it was too hard, or it was too high, or it was too dangerous. No, I’ve learned that there [are] things that Edward can do that maybe we don’t think he’s capable of, but he can do it.

Another theme that emerged as parents spoke about the ways in which Special Olympics had elevated their expectations was the idea that Special Olympics afforded their children the opportunity to demonstrate their autonomy, whether through competition or through opportunities to go on overnights. Often, Special Olympics allows parents a different perspective by giving them the opportunity to see their sons and daughters engage in a variety of normative developmental tasks independently, without the typical levels of supervision and intervention that may be present in other aspects of their lives (e.g., at home, at school, and even at work).

You get yourself thinking that they really can’t do anything without you, and you find out that yes, they can do this without you really well. They don’t really need you, and he gets along fine with other people, and he can go away and spend the night in a hotel and manage himself just fine.

In summary, parents view their children with intellectual disabilities very positively, and easily identify their strengths. However, they acknowledge that societal perceptions of people with intellectual disabilities can be quite different, and others often fail to recognize the many positive characteristics, and indeed the basic humanity, of their

children with intellectual disabilities. Family members recognized that Special Olympics had contributed to their positive perceptions by allowing them to see their children's independence and competence, and by giving them the opportunity to cheer their accomplishments on the playing field. These opportunities, in many instances, contributed to the heightened expectations of both parents and siblings.

Question 2: How Do Families Believe that Participation in Special Olympics Benefits Their Children with Intellectual Disabilities?

Parents almost unanimously agreed that Special Olympics had a positive impact on their daughters and sons in a variety of ways. The most frequently cited benefits perceived by parents were 1) the opportunities for social engagement and development (69%); 2) positive impact on self-concept (35%); 3) the opportunity to participate (34%); and 4) physical benefits (29%) (see Table 3). These findings are similar to those of Siperstein and colleagues (2005) who found that parents believed Special Olympics provided athletes with opportunities for social growth and personal development.

Parents commented extensively on the social benefits that their children gleaned from participation in Special Olympics. This is not surprising given that parents generally assign great value to opportunities that allow their children with intellectual disabilities to increase their peer interactions and develop social skills. The opportunity to form meaningful friendships is a normative and essential developmental task during childhood and adolescence (e.g., Dunn & McGuire, 1992). One father illustrated the significance of the opportunities for friendship that Special Olympics offers these youth:

She met her best friend ... through Special Olympics... They like all the same things. They're two years apart in age. They get along beautifully. And Karen never had a friend like this her entire life until she was about 18-years-old. And now for the last five years, these two – they sleep over

each other's houses, their family takes Karen to events, we take their daughter to events. And they've gotten closer and closer as time has gone on. And both of us parents have said we only wish they could have met each other when they were five years old.

Table 3: Parental perceptions of the benefits of Special Olympics for athletes

Benefit to individual	Description	Example
Social	Increased social contact; friendship formation; development of social skills	<p>"She's met a lot of great people"</p> <p>"It brought him out of his shell."</p> <p>"He's made a lot of friends."</p> <p>"I think the biggest thing is the social aspect."</p>
Self-concept	Improved self-esteem; pride; sense of accomplishment	<p>"It gives her more confidence."</p> <p>"He knows he can – he knows what he can do now."</p> <p>"He's become more independent, and he's become more self-reliant, and he can feel proud of himself."</p>
Participation	Increased participation in activities or in the community; new experiences; inclusion	<p>"Activity – mostly activity. It keeps him busy."</p> <p>"I guess being part of a team. He likes to be included. He doesn't like to feel left out."</p> <p>"...makes him feel like he's a valuable part of society."</p> <p>"She's gotten to see and do a lot of things that she wouldn't have gotten to do."</p>
Physical	Exercise; better health; improved athletic ability	<p>"He's in pretty good shape for a boy with Down syndrome."</p> <p>"It's really helped improve her motor skills."</p>

Many parents also stressed the value of Special Olympics in promoting their child's self-concept. They felt that Special Olympics, through the opportunities it provides for healthy competition, enabled their athletes to set and accomplish goals, demonstrate their abilities, and receive recognition for success. Special Olympics also appears to impact athletes' developing sense of self by providing opportunities for athletes to spend time away from their families, attending competitions that frequently

take them away from home, often on overnights, thus reinforcing their emerging sense of autonomy. Parents perceived that these opportunities, not always readily available to individuals with intellectual disabilities, fostered increased confidence, independence, and self-esteem in their children. Again, these experiences and their positive consequences are a more common phenomenon for non-disabled youth, who often have many opportunities, through sport and other activities, to engage in experiences that promote a healthy self-concept.

Parents also believed that just being given the opportunity to participate in an activity was an important benefit of Special Olympics for their child. In fact, parents saw Special Olympics as more than an opportunity to participate in a sports activity but also as an opportunity to participate as a member of society. Although related, this benefit is perceived as separate from the opportunity for socialization and friendship, as it relates more to the opportunities for activity outside the home and inclusion in a wider community. There was a general sense that if not for Special Olympics, their children would spend a lot of time at home alone, “watching television and playing video games.”

This perception by parents that Special Olympics is “the only game in town” appears to be an accurate representation of the opportunities for recreation and active involvement that are available for most young people with intellectual disabilities. There is ample evidence to suggest that these opportunities are not widely available to adolescents and young adults with intellectual disabilities (e.g., Buttimer & Tierney, 2005; Dattilo & Schlein, 1994). Again, the message was conveyed that adolescents and young adults with intellectual disabilities are often excluded from activities that typically developing youth experience regularly. These experiences include playing sports, being

part of a team, and being included in social events. Parents often talked about these opportunities in comparison to their other children. Generally, when there are other children in the family, those siblings have had many opportunities to engage in these normative activities. When youth with intellectual disabilities are involved in Special Olympics, it frequently means that they can enjoy the same activities as their brothers and sisters. As one father said, “I played ball when I was in high school, and my older boy played, and Kevin really couldn’t. Well, now he can.”

Siblings also recognized the value of Special Olympics for their brothers and sisters. Similar to parents, siblings almost unanimously agreed that Special Olympics had a positive impact on their brothers and sisters. Paralleling parental responses, siblings described social benefits, greater involvement, and improved self-concept as the greatest advantages. Most (61%) felt that the athlete had become more social since becoming involved in Special Olympics. One sibling said, “She used to be a shy kid that didn’t really want to be around people, and now every time she’s around her teammates she’s the one that’s cheering them on and screaming.” Siblings also frequently responded that their brothers and sisters had become more active and more involved in activities outside the home (54%). For example, “He’s more active; exercise of course, [but also] meeting new people, getting out there, and seeing more what the real world is about.” Siblings often described their brothers’ and sisters’ lack of activity prior to Special Olympics, suggesting that they too believed Special Olympics offered a rare opportunity for their sisters and brothers to get involved in activities outside of the home. As one sibling stated, “she used to not do a lot... She got really excited about Special Olympics and she tells us all about it.” Many siblings (39%) also felt that their brother or sister had

developed a more positive sense of self since getting involved in Special Olympics (“She feels better about herself. It’s something she can say she accomplished.”)

Family members unanimously agreed that athletes benefit in critical ways from their involvement in Special Olympics. It is of interest that sibling responses paralleled those of their parents, suggesting not only the strength of these positive impacts, but also the value that all family members place on opportunities for social development, engagement in an active lifestyle in the community, and enhanced self-concept.

Question 3: How Are Family Members Involved in Special Olympics and How Does Involvement Benefit Families?

Family members’ involvement in Special Olympics. Based on the primary parents’ report, in the vast majority of families (82%), at least one parent attended their child’s competitions most of the time or always. In those families in which there was at least one sibling present (n = 100), 45% of siblings attended most of the time or always (see Table 4). Regardless of how often they actually attended, parents and siblings with whom we spoke repeatedly told us that they attended “as often as I can.”

Table 4. How often do family members attend competitions?*

	Mothers (n=120)	Fathers (n=101)	Siblings (n = 100)
Always	54%	43%	21%
Most of the time	22%	31%	24%
Once in a while	8%	9%	28%
Never	17%	18%	27%

*based on primary parent report

In most families (75%), family members had been involved in the Special Olympics organization at some level beyond attending competitions. The most

frequently reported types of involvement were coaching and volunteering (including chaperoning) at an event (See Table 5). For fathers, the most common type of involvement was coaching; 30% of the fathers were involved in Special Olympics as coaches. Mothers and siblings were more likely to be involved as volunteers at events (26% and 19%, respectively).

Table 5. How are families involved in Special Olympics?

Type of involvement	n	percent
Coached	52	42%
Volunteered or chaperoned at an event	49	39%
Participated in fundraising, publicity, or recruitment activities	30	24%
Played as a Unified Partner	21	17%
Involved in other Special Olympics Programs (e.g., Athlete Leadership Program, Family Support Network)	4	3%
Participated in some other way	23	18%

* Totals to more than 100% because some families are involved in multiple ways.

In looking at the relationship between athlete and family involvement in Special Olympics, it was perhaps not surprising, that there was a moderate positive correlation between an athlete’s length of involvement in Special Olympics and family members’ involvement ($r = .37$; $p < .001$). Athletes who had participated in Special Olympics for a greater length of time had family members who were more involved in Special Olympics, particularly as coaches ($r = .35$; $p < .001$) or as volunteers ($r = .24$; $p < .01$).

Involvement in Special Olympics can mean different things for different families. Families differed in both their amount of involvement with Special Olympics and in the form that involvement took, whether attending competitions to cheer on the athletes or

taking on other roles, such as coach, chaperone, or Unified partner within the organization. Clearly, families felt their attendance at events was important and tried to attend as often as possible. Further, families tended to become increasingly involved in Special Olympics over time, indicating that the Special Olympics organization provides both athletes and their families with a strong sense connection and commitment.

Direct benefits of family involvement in Special Olympics. This overall high level of involvement appears to offer at least two direct advantages to families, strengthening relationships within the family and providing a source of social support for families. First, family members identified the value of Special Olympics to their family as a whole. The majority of parents felt that Special Olympics provided an opportunity for them to bond as a family thus strengthening relationships. Specifically, over two-thirds of parents (70%) felt that Special Olympics had at least some impact on the time they spent together as a family (either the amount of time they spent together or the types of activities that they shared). There was clear recognition among these parents that Special Olympics provides opportunities for families to come together for fun and recreation around their children with and without intellectual disabilities that might otherwise be lacking. One father in a family who had been involved in Unified Sports, said this:

Well, it's just been another way for us to have a family activity. It's hard sometimes to find things to do as a family. Everybody [wants] their own way as they get older. This is one thing that we could use to pull everyone back doing the same thing for a short period of time but nonetheless we can do it and treat is a family function.

Siblings also assigned great value to their families' involvement in Special Olympics. Most siblings (82 %) felt that Special Olympics had indeed impacted their families, all for the positive. Of these, over half (57%) felt that participation in Special

Olympics had brought their family closer together. For example, one sibling described how Special Olympics brought the family closer by helping her sister (the athlete) and her mother find a common interest; “my sister loves basketball and baseball and my mom loves baseball so it brings everyone closer.” Many siblings (44%) felt that Special Olympics provided a rare opportunity for the whole family to share an activity (“It gives the whole family a time to get together”), and over one-third (39%) of siblings felt that Special Olympics provided their families with a normative experience they could share. According to one sibling, attending events “helps the family develop and feel more normal.” Other siblings reported similar sentiments drawing comparisons between Special Olympics and school- and community-based sports teams for typically developing youth. “It’s a chance for my parents to have the same joy watching him as they did with my brother and [me].”

Further, almost one-quarter (22%) of siblings reported that Special Olympics had improved their own relationship with their brother or sister. “I just get closer to him when I go to things and see him compete and get to know him a bit better.” In general, siblings appear to value Special Olympics for many of the same reasons that their parents do. Not only do they recognize the variety of benefits that their brothers and sisters derive from their involvement, they also recognize the positive impact that Special Olympics has had on their families by providing opportunities for families to find common ground with each other and to share in normative experiences.

Finally, family involvement was an important part of the Special Olympics experience for athletes, as well. Athletes were overwhelmingly positive when talking about their family members’ involvement. Over half (53%) of the athletes said that

family attendance made them happy (“It makes me feel happy when they're there with me.”). Almost one-quarter of the athletes (22%) additionally reported that they felt supported and encouraged when family members attended games (“I like it because they're there to support me.”). Conversely, lack of attendance seemed to be felt negatively by the athlete. Although we spoke to very few athletes whose families did not attend Special Olympics events, one athlete told us that this made him think “that maybe they don't care about me.”

Second, Special Olympics also appears to be a source of social support for families, impacting the connections that parents forge beyond their family circles. Just as Special Olympics appears to play an important role in the social lives of athletes, parents also report that it has a substantial impact on their own social support network. Specifically, 75% of responding parents said that Special Olympics had had at-least some impact on their social relationships outside the family, and over one-third of those (38%) felt that it had a lot of impact.

Furthermore, there was a moderate relationship between a parent's belief that Special Olympics had impacted their relationships outside the family and their family's level of involvement in the Special Olympics organization ($r = .32$; $p < .01$). In other words, parents who had families who were more involved in Special Olympics (involved in some way beyond attending events) also tended to believe that Special Olympics had impacted their social relationships outside the family. Clearly, for these families, Special Olympics provided a strong sense of community. They attended events regularly, got involved in the organization as volunteers, coaches, and Unified partners, and also socialized with other Special Olympics families. These parents frequently referred to the

friendships they had developed and the opportunities to socialize with other families (“Most of our friends are Special Olympics parents”). Generally speaking, parents frequently develop friendships with the families of their children’s peer group. Unfortunately, because children with intellectual disabilities are often isolated from their peers and excluded from community recreational programs, their parents do not always have these opportunities. One mother described the value that she derived from her involvement in Special Olympics this way:

Special Olympics has introduced me to three other families, and the moms – we’re like – it’s a group. On Saturdays when they bowl, that’s our time to sit and talk and cry on each others’ shoulders or be proud or happy. It’s brought us together. I’ve made a lot of friends.

Parents frequently spoke of the support networks they had been able to establish through their involvement with Special Olympics. They often mentioned the value that they place in being able to talk with parents who have had similar experiences and whose children face similar challenges. As one mother said, “there’s always somebody there that understands what you’re dealing with.” Parents of children with disabilities often face challenges that are quite different from those of typically developing children. Parents often mentioned that the people they met through their involvement with Special Olympics were not just a source of emotional support, but also a valuable source of information about school and community services and programs.

Parents who had high levels of involvement in the Special Olympics organization clearly perceived Special Olympics as a positive engine of connection for both their children and themselves. They also saw Special Olympics as a valuable resource to the larger community (“It’s a good cause, and it’s a good idea.”) Thus, they often described the feelings of personal gratification and fulfillment that can come along with being

involved in one's community in a meaningful way. One father who was also a track and field coach, said, "I get just as much as they get out of it – to see them succeed."

Just as parents and siblings talked about the importance of participation and involvement for athletes, we see a similar theme emerging for parents. Both youth with disabilities and their parents may often feel excluded from the broader community (of families). Given the importance of a sense of community for healthy development and well-being at all life stages (Davidson & Cotter, 1991), the level of involvement and participation that Special Olympics affords to both athletes and their families must be acknowledged as a truly valuable asset.

Summary of Results

This study builds on previous work (e.g., Siperstein et al., 2005; Weiss et al., 2003) by exploring the benefits that Special Olympics affords its athletes and extends this work by focusing on families, revealing the many ways that they contribute to Special Olympics and that Special Olympics contributes to their well-being. To summarize, this study revealed the following findings:

- 1) Families talked about their children with intellectual disabilities very positively and expressed great pride in their many accomplishments. It was also clear that participation in Special Olympics contributed to family members' positive perceptions. Athlete's participation in Special Olympics, helped their families see them as autonomous individuals with a range of strengths and abilities. As a result, the majority of family members reported

that participation in Special Olympics had helped raise their expectations of their athletes.

- 2) Family members agreed that Special Olympics provided their athletes with a range of benefits. Both parents and siblings recognized the value of Special Olympics for the social development of athletes. An overwhelming majority of family members said that because of their participation in Special Olympics, athletes had developed social skills, expanded their peer networks, and established meaningful friendships. Parents and siblings also agreed that Special Olympics had provided athletes with opportunities to increase their levels of active participation in the community and develop a healthy sense of self.
- 3) On average, families reported high levels of involvement in Special Olympics, although there was a considerable range in both intensity and type of involvement. Many family members attended events most of the time or always, and there was general agreement that they tried to attend as often as possible. A large number of families had taken on additional roles in the Special Olympics organization, such as volunteer, chaperone, coach, or Unified partner. Further, there was a relationship between level of family involvement and length of time an athlete had participated in Special Olympics, indicating that families became increasingly involved in Special Olympics over time.
- 4) Families derived two direct benefits from their involvement in Special Olympics. First, many parents and siblings felt that Special Olympics

provided opportunities for the whole family to come together for fun and recreation and thus had helped strengthen relationships within the family. Second, most parents believed that Special Olympics had had an impact on their connections outside the family, providing them with opportunities to meet and socialize with other families and be meaningfully involved in the community.

Conclusions

Based on these findings, we can draw two key conclusions. First, Special Olympics operates as a powerful engine of connection for athletes and their families. Second Special Olympics provides athletes and their families with normative life experiences that are critical to healthy development.

Special Olympics operates as an engine of connection

It provides opportunities for athletes and their families to forge new relationships and strengthen existing ones. Parents and siblings credited Special Olympics with providing athletes with much needed opportunities for making friends and becoming actively engaged in meaningful activities outside the home. Many expressed the sentiment that without Special Olympics, athletes would spend a lot of time at home. Young people with intellectual disabilities often engage in leisure activities that are home-based and solitary in nature (Buttimer & Tierney, 2005; Dattilo & Schlein, 1994; McEvoy, O'Mahoney, & Tierney, 1990; Richardson, Katz, & Koller, 1993), even though parents identify involvement in recreational activities as essential to the quality of life of their children with intellectual disabilities (McIntyre, Kraemer, Blacher, & Simmerman,

2003), and individuals with intellectual disabilities have expressed the desire to be more involved in their communities (Kampert & Goreczny, 2005).

Not only does the presence of Special Olympics establish a community in which young people with intellectual disabilities can be active participants and feel connected, it also provides its athletes with opportunities develop social relationships with peers, and experience the deep bonds of true friendship. The formation of peer relationships is a normative and essential developmental task during childhood and adolescence. Its successful mastery provides the foundation for future outcomes, especially in the transition to adulthood (Bukowski & Hoza, 1989; Dunn & McGuire, 1992). Youth with developmental disabilities, however, may have limited opportunities to engage in regular interactions with peers and establish meaningful friendships (Gresham & MacMillan, 1997; Guralnick, 1999; Nowicki, 2003). Thus, Special Olympics plays a very important role for its athletes by providing these social opportunities.

Further, for a substantial majority of parents, Special Olympics had a similar impact on their own social relationships, providing them with opportunities to expand their circle of social support outside the family and become involved in a cohesive community in which they share common interests, concerns, and values. Social support is a critical source of well-being for all families, and perhaps especially for families of youth with disabilities (Osofsky & Thompson, 2000). For example, social support has been associated with reduced parenting stress in mothers (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001) and increased parenting confidence in fathers of children with disabilities (Kersh, Hedvat, Hauser-Cram, & Warfield, 2005). Thus, we can conclude

that Special Olympics offers families a deep sense of connection that contributes to their general well-being.

Many parents and siblings also said that Special Olympics had positively impacted the time they spent together as a family, providing regular opportunities for family members to have fun together, whether attending a Special Olympics event or shooting baskets on the weekend. Shared recreation time is an important part of family life. Not only does it contribute to the healthy development of the child, it promotes overall family health and well-being (Black & Lobo, 2008). Thus, by providing opportunities for shared recreation, Special Olympics may contribute to positive family functioning and improved family relationships.

Special Olympics seems to be particularly important in strengthening sibling relationships. Of the siblings interviewed, almost all of them attended Special Olympics competitions as often as they could, over half were involved in Special Olympics in some other way beyond attending competitions, and over three-quarters felt that Special Olympics had had a positive impact on their families. Many said that Special Olympics had impacted their own relationship with their brother or sister. Certainly, the vast majority of siblings agreed that Special Olympics had changed their perceptions of their brothers and sisters, and helped them see them as more competent, social, and independent individuals. Although sibling relationships in families of children with intellectual disabilities are often characterized by great warmth and affection, the non-disabled sibling frequently takes on the role of caregiver and helper (e.g., Hannah & Midlarsky, 2005; Stoneman, 2001). Our results suggest that Special Olympics may promote more reciprocal, peer-like relationships by providing opportunities for siblings

to share recreational experiences and bond over common interests, as well as providing typically-developing siblings with the opportunity to see their brothers and sisters as capable, successful, and socially accepted.

Special Olympics provides opportunities for normative life experiences.

Typically developing youth in the United States generally have a variety of opportunities to engage in sports and recreational activities in their schools and communities. We have come to understand these opportunities as a normative part of life for young people and their families, essential for the healthy social and emotional development of both the child and the family. Children, through their engagement in organized extracurricular sports and recreational activities, develop important social skills and a healthy sense of self (Lareau, 2003). Unfortunately, children with intellectual disabilities are often excluded from these activities and thus, generally have fewer opportunities to participate in experiences that promote social and emotional development. Special Olympics clearly provided these opportunities for the youth in this study. Our findings indicate that youth with intellectual disabilities derive the same benefits from these opportunities as typically developing youth. Certainly, parents felt that Special Olympics had positively impacted their sons' and daughters' development, particularly in the areas of social development, peer relationships, and self-concept, and this view was reinforced by sibling perceptions, suggesting that these perceived benefits, are, in fact, real.

In talking to parents, it became clear that Special Olympics offers yet another, perhaps unanticipated, opportunity for athletes to engage in a normative experience. In addition to the opportunities to engage in athletic training and competition, going to

regional and state events (and beyond) took athletes away from home, often on overnights. Throughout the interviews, parents spoke about these overnight experiences and their importance. These trips offered a rare chance for athletes to be away from their families and experience a new level of independence. While most typically-developing youth have many chances to experience being away from home, both informally (sleeping-over at a friend's house) and formally (attending summer camp and going on school trips) throughout childhood, many young people with intellectual disabilities have very few opportunities to experience these normative events. In one parent's words, "It's the only place she gets to sleep over somewhere...She feels a sense of normalcy, I think."

Clearly the normative experiences offered by Special Olympics are important to the healthy development of the athlete, but they also contribute to the well-being of the family. When individuals with intellectual disabilities are deprived of these experiences, so are their families. Special Olympics provides family members with important opportunities to see their children acquire a range of skills and experience success. They get to cheer their accomplishments. Thus, family members are better able to perceive Special Olympics athletes as independent, competent individuals. These experiences appeared to contribute to the elevated expectations that parents (and siblings) ascribed to their child's participation in Special Olympics. This study indicates that Special Olympics places youth with intellectual disabilities and their families at promise by providing these critical normative opportunities.

Final Thoughts

This study has been guided by the spirit of positive psychology, which has allowed us to focus on how Special Olympics has contributed to the happiness, well-

being, and healthy development of individuals with intellectual disabilities and their families. This is, unarguably, a very useful framework for moving forward with future investigations of the impact of Special Olympics on individuals and families. However, it is not the only theoretical model that is appropriate to this work. Family Systems Theory (Minuchin, 1988) is also an important model to help us frame the results of this study.. Family Systems Theory reminds us that the family is a holistic system that is: (a) composed of interdependent elements (people) that contribute to the overall functioning of the system as a whole; (b) also comprised of interacting and overlapping subsystems (relationships within the family such as the parent-child, sibling, and marital subsystems), such that the quality of functioning in one subsystem impacts the quality of functioning in the other subsystems; and (c) an open system that develops and changes in response to shifting circumstances and contexts. Such an understanding helps us better appreciate the multiple ways, both direct and indirect, in which Special Olympics impacts both its athletes and their families. Really, it is not possible to consider the benefits to one, without considering the benefits to the other. When the child is positively impacted, so is his family; when the family benefits, so does the child. The results of this study indicate that the Special Olympics community may serve as a vital context for promoting these mutually beneficial and reciprocal benefits.

REFERENCES

- Blacher, J., & Baker, B. L. (2007). Positive impact of intellectual disability on families. *American Journal on Mental Retardation, 112*, 330-348.
- Black, K., & Lobo, M. (2008). A conceptual review of family resilience factors. *Journal of Family Nursing, 14*, 33-55.
- Bukowski, W. M., & Hoza, B. (1989). Towards a further understanding of peer relationships and their contributions to child development. In T. J. Berndt & G. W. Ladd (Eds.), *Peer relationships in child development* (pp. 15-45). New York: John Wiley.
- Buttimer, J., & Tierney, E. (2005). Patterns of leisure participation among adolescents with a mild intellectual disability. *Journal of Intellectual Disabilities, 9*, 25-42.
- Dattilo, J., & Schlein, S. J. (1994). Understanding leisure services for individuals with mental retardation. *Mental Retardation, 32*, 53-59.
- Davidson, W. B., & Cotter, P. R. (1991). The relationship between sense of community and subjective well-being: A first look. *Journal of Community Psychology, 19*, 246-253.
- Dunn, J., & McGuire, S. (1992). Sibling and peer relationships in childhood. *Journal of Child Psychology and Psychiatry, 33*, 67-105.
- Dykens, E. M. (2005). Happiness, well-being, and character strengths: Outcomes for families and siblings of persons with mental retardation. *American Journal on Mental Retardation, 43*, 360-364.
- Dykens, E. M., & Cohen, D. J. (1996). Effects of Special Olympics International on social competence in persons with mental retardation. *Journal of the American Academy of Child & Adolescent Psychiatry, 35*, 223-229.
- Eisenberg, L., Baker, B. L., & Blacher, J. (1998). Siblings of children with mental retardation living at home or in residential placement. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 39*, 355-363.
- Farber, B. (1959). The effects of severely retarded children on the family system. *Monographs of the Society for Research in Child Development, 24*(2, Serial No. 7)
- Farber, B. (1960). Perceptions of crisis and related variables in the impact of a retarded child on the mother. *Journal of Health and Human Behavior, 1*(2), 108-118.
- Favazza, P. C., & Siperstein, G. N. (2006). Evaluation of Young Athletes Program 2006. Washington, D.C.: Special Olympics, Inc.

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- Gresham, F. M., & MacMillan, D. L. (1997). Social competence and affective characteristics of students with mild disabilities. *Review of Educational Research, 76*, 377-415.
- Guralnick, M. J. (1999). The nature and meaning of social integration for young children with mild developmental delays in inclusive settings. *Journal of Early Intervention, 22*, 70-86.
- Hannah, M. E., & Midlarsky, E. (2005). Helping by siblings of children with mental retardation. *American Journal on Mental Retardation, 110*, 87-99.
- Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., & Krauss, M. W. (2001). Children with disabilities: A longitudinal study of child development and parent well-being. *Monographs of the Society for Research in Child Development, 66* (3, Serial No. 266).
- Helff, C. M., & Glidden, L. M. (1998). More positive or less negative? Trends in research on adjustment of families rearing children with developmental disabilities. *Mental Retardation, 36*, 457-464.
- Jordan, T. E. (1962). Research on the handicapped child and the family. *Merrill-Palmer Quarterly, 8*, 243-260.
- Kampert, A. L., & Goreczny, A. J., (2007). Community involvement and socialization among individuals with mental retardation. *Research in Developmental Disabilities, 28*, 278-286.
- Kersh, J. (2007). *Understanding sibling relationships when one child has a disability*. Unpublished dissertation.
- Kersh, J., Hedvat, T. T., Hauser-Cram, P., & Warfield, M. E. (2006). The Contribution of Marital Quality to the Well-Being of Parents of Children with Developmental Disabilities. *Journal of Intellectual Disability Research, 50*, 883-893.
- Klein, T., Gilman, E., & Zigler, E. (1993). Special Olympics: An evaluation by professionals and parents. *Mental Retardation, 31*, 15-23.
- Lareau, A. (2003). *Unequal childhoods*. Berkeley: University of California Press.
- McEvoy, J., O'Mahoney, E., & Tierney, A. (1990). Parental attitudes to friendship and use of leisure by mentally handicapped persons in the community. *International Journal of Rehabilitation Research, 13*, 269-271.
- McIntyre, L. L., Kraemer, B. R., Blacher, J., & Simmerman, S. (2004). Quality of life for young adults with severe intellectual disability: Mothers' thoughts and reflections. *Journal of Intellectual & Developmental Disability, 29*, 131-146.

- Minuchin, P. P. (1988). Relationships within the family: A systems perspective on development. In J. Stevenson-Hinde (Ed.), *Relationships within families: Mutual influences* (pp. 7-26). New York: Oxford Press.
- Nowicki, E. A. (2003). A meta-analysis of the social competence of children with learning disabilities compared to classmates of low and average to high achievement. *Learning Disability Quarterly*, 26, 171-188.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework*, 43, 190-193.
- Osofsky, J. D., & Thompson, D. (2000). Adaptive and maladaptive parenting: Perspectives on risk and protective factors. In J. P. Shonkoff & S. J. Meisels (Eds.), *Handbook of early childhood intervention* (2nd ed., pp. 54-75). New York: Cambridge University Press.
- Richardson, S. A., Katz, M., & Koller, H. (1993). Patterns of leisure activities of young adults with mild mental retardation. *American Journal on Mental Retardation*, 97, 431-442.
- Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation*, 38, 195-206.
- Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist*, 55, 5-14.
- Siperstein, G. N., Harada, C. M., Parker, R. C., Hardman, M. L., & McGuire, J. (2005). A comprehensive national study of Special Olympics programs in the United States. Washington, D.C.: Special Olympics, Inc.
- Solnit, A. J., & Stark, M. H. (1961). Mourning and the birth of a defective child. *Psychoanalytic Study of the Child*, 16, 523-537.
- Stainton, T., & Besser, H. (1998). The positive impact of children with an intellectual disability on the family. *Journal of Intellectual and Developmental Disability*, 23, 57-70.
- Stoneman, Z. (2001). Supporting positive sibling relationships during childhood. *Mental Retardation and Developmental Disabilities Research Reviews*, 7, 134-142.
- Taunt, H. M., & Hastings, R. P. (2002). Positive impact of children with developmental disabilities on their families: A preliminary study. *Education and Training in Mental Retardation and Developmental Disabilities*, 37, 410-420.
- Van Riper, M. (2000). Family variables associated with well-being in siblings of children with Down syndrome. *Journal of Family Nursing*, 6, 267-286.

- Wagner, M., Cadwallader, T., Garza, N., & Cameto, R. (2004, March). Social activities of youth with disabilities: NTL2 data brief (Vol. 3, Issue 1). Retrieved on-line October 10, 2008, from <http://www.ncset.org/publications/viewdesc.asp?id=1470>
- Weiss, J. A. (2008). Role of Special Olympics for mothers of adult athletes with intellectual disability. *American Journal on Mental Retardation*, *113*, 241-253.
- Weiss, J., Diamond, T., Demark, J., & Lovald, B. (2003). Involvement in Special Olympics and its relations to self-concept and actual competency in participants with developmental disabilities. *Research in Developmental Disabilities*, *24*, 281-306.

APPENDICES

- A. Letter to families
- B. Screening Questionnaire
- C. Primary Parent Interview
- D. Secondary Parent Interview
- E. Sibling Interview
- F. Athlete Interview

APPENDIX A – Letter to families



August 21, 2007

Dear Special Olympics Athletes and Families,

We are writing to share some exciting developments at Special Olympics and ask for your help. We have already learned a great deal about the benefits of participation in Special Olympics for athletes. For example, we have learned that through their involvement in Special Olympics, athletes gain self-esteem, experience health benefits, and make friends. We are now launching a new project to explore the ways that families benefit from their associations with Special Olympics, as well as the potential challenges that might be involved. We want to talk with mothers, fathers, brothers and sisters and hear what they have to say about their families, the relationships they share, and their Special Olympics experiences.

We invite you to be an important part of this project. During the next six weeks, you may receive a telephone call from one of our trained interviewers. We ask that you take the time to answer their question and share your stories. If you have questions about this project, you may contact the project director, Dr. Joanne Kersh, at 617-287-7250; her email address is joanne.kersh@umb.edu.

We look forward to talking with you soon.



Dr. Stephen B. Corbin
Special Olympics Senior VP of Constituent Services and Support

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Created by the Joseph P. Kennedy, Jr. Foundation. Authorized and Accredited by Special Olympics, Inc., for the Benefit of Persons with Mental Retardation.

APPENDIX B – Screening Questions

[If you get answering machine/voicemail: (Only leave message once-see call log on front page if unsure whether to leave a message or not).]

Hello, my name is _____. I'm with Special Olympics and am calling as part of a national study about athletes and their families. I will try calling you back another time. Thank you.

=====

[If child/adolescent answers the phone:]

Hello, my name is _____. I'm with Special Olympics. Is your mom or dad available?

=====

[If parent not available:]

Ok, is there a better time I could reach them? _____
Thank you.

=====

[When adult is on the phone:]

INTRODUCTION/SCREENING

Hello, my name is _____. I'm with Special Olympics and I'm calling as part of a national study about athletes and their families. Your state Special Olympics program is part of the project, and your family has been randomly selected to participate. We sent letters to families describing our project a few weeks ago. I hope you received one. We want to learn more about the families who are involved in Special Olympics. We are interested in talking with mothers, fathers, brothers and sisters to hear what you have to say about your family and your Special Olympics experiences. Would you be willing to participate?

First, I have a few brief questions to confirm our records.

1. Do you have a son or daughter who has participated in Special Olympics?

- Yes → **[PROCEED TO QUESTION 2]**
- No → **[ASK FOLLOW-UP, THANK AND TERMINATE]**

a. **[IF NO]** Does he/she play any sports through a school, or other community organization?

- Yes (Describe: _____)
- No

THANK AND TERMINATE

2. What's his/her name? _____

3. Gender **[CODE ONLY - DO NOT ASK UNLESS UNSURE]**

Male

Female

4. Has [ATHLETE] trained or competed in any Special Olympics sport in the last year?

Yes

No

a. **[IF NO]** how long has it been since s/he was last involved in Special Olympics?

5. Does he/she live with you?

Yes

No

a. **[IF NO]** Where does athlete live?

6. How old is [ATHLETE]? AGE: _____

ATHLETE MUST HAVE PARTICIPATED IN SPECIAL OLYMPICS WITHIN THE LAST YEAR, BE BETWEEN THE AGES OF 12 AND 30, AND LIVE AT HOME TO PARTICIPATE IN THIS PROJECT

[IF ATHLETE IS NOT ELIGIBLE]

Thank you. This particular project focuses on younger (or older) athletes (OR athletes who are living at home OR athletes who are currently active). However, what you have to say is still very important to us, and your family may fit the profile for another project. Can we keep your information on file and call you in the future?

Yes

No

[IF ATHLETE IS ELIGIBLE]

Thank you. I have some questions for you about your family and your involvement in Special Olympics, which will take about 20-25 minutes. If this is a good time, we can start now.

Yes → **[PROCEED WITH INTERVIEW]**

No → **[SCHEDULE A CALL BACK AND GET PARENT'S NAME]**

APPENDIX C - PRIMARY PARENT INTERVIEW

INFORMED CONSENT

Before we begin, I want you to know that all information will be kept anonymous. Your name will not be connected with anything you say, and I won't share what you tell me with anyone else (unless you were to tell me that you or somebody else is in danger). You may choose not to answer any question. If you have any questions or concerns about the project, I can give you a phone number to call. **[IF THEY ASK, GIVE THEM JOANNE KERSH'S NUMBER: (617) 287-7241.]** Do you have any questions?

May I record our conversation?

[IF PARENT IS HESITANT OR ASKS WHY, TELL THEM IT'S THEIR DECISION TO BE TAPED OR NOT, BUT WE'D LIKE TO TAPE IT IN ORDER TO CAPTURE EXACTLY WHAT THEY SAY IN THEIR OWN WORDS. ALSO, ADD IN SOMETHING ABOUT NOT BEING A FAST WRITER TO KEEP UP WITH WHAT THEY SAY.]

State intellectual disabilities# before continuing with the interview

1. What is your relation to [ATHLETE]?

- Mother
- Father
- Other: _____

2. First I'd like to find out about who lives in your household.

[COMPLETE GRID – ASK PARENT TO LIST EACH MEMBER OF THE HOUSEHOLD AND RELATIONSHIP TO ATHLETE. THEN ASK IF THERE ARE ANY OTHER FAMILY MEMBERS THAT HAVEN'T BEEN LISTED – I.E., THOSE WHO DO NOT LIVE AT HOME – OLDER SIBLINGS OR ANOTHER PARENT]

Name	Relationship	Live at home? (Y/N)	Age (if sibling)	Comments

Total # adults in household _____

Total # children in household _____

Total # sibs _____

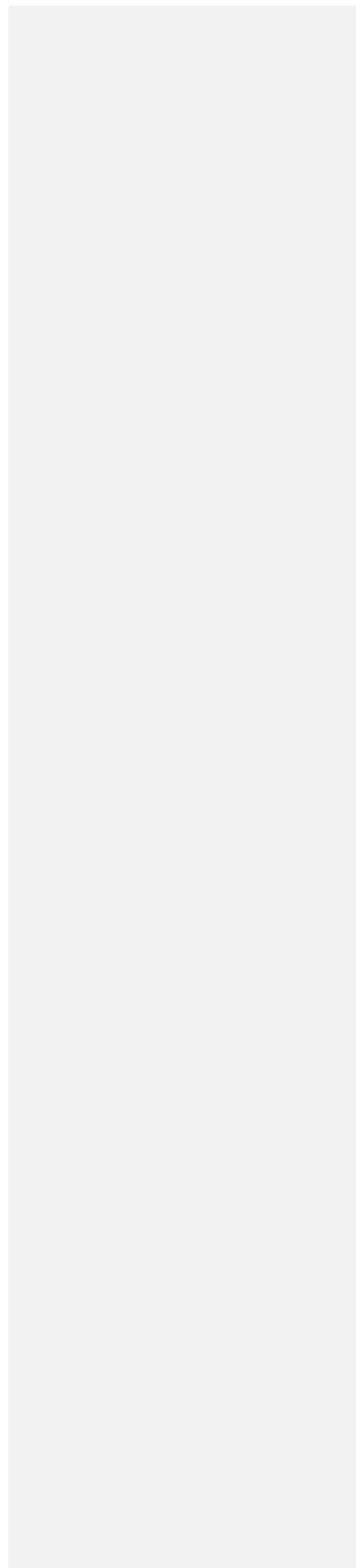
Now I'd like to ask you some questions about [ATHLETE].

3. What are some of things that you and [ATHLETE] do together?
[Probe for one-on-one and whole family activities]

4. Describe [ATHLETE]'s strengths?

5. What would you like people to know about [ATHLETE]?

6. Can you tell me about a time when [ATHLETE] has made you proud?



7. What have you learned from being [ATHLETE]'s parent?

8. What do you think is the most challenging part of being his/her parent?

SIBLING RELATIONSHIPS

Now, I'd like to ask some questions about [ATHLETE]'s relationship with his/her brother(s) / sister(s).

[IF ONLY 1 SIB, SKIP TO 10]

9. Is there a sibling s/he's particularly close with?
[If NO, ask about sibling closest in age]

a.) Sibling name: _____ b) Age: _____

c) brother OR sister

10. What do they do together?
[Probe for a range of activities]

11. What is the best part of their relationship?
[Probe if necessary: good, positive part of the relationship]

12. What does [ATHLETE] get out of the relationship?
[Don't ask if already answered]

13. What does [SIBLING] get out of the relationship?
[Don't ask if already answered]

14. What do you think is the most challenging part of their relationship?
[Probe for challenges for each sibling]

Wow, it sounds like they have a nice/great/interesting relationship. We also have a brief sibling interview. It's really important to hear from brothers and sisters of Special Olympics athletes, as well as from moms and dads. Do you think that [SIBLING] would also be interested in speaking with me a little later for 5 or 10 minutes? We can talk about it a little more when we're finished.

SPECIAL OLYMPICS PARTICIPATION

Now I'd like to ask you some questions about Special Olympics.

15. How long has [ATHLETE] participated in Special Olympics?

a. Note age when athlete first became involved _____

16. How did [ATHLETE] initially become involved in Special Olympics? (e.g., school or other organization)

17. What sports has he/she played in Special Olympics?

(Open ended and code, ALLOW SIX RESPONSES)

(INTERVIEWER NOTE: If respondent says "skiing" or "skating", Probe for type)

- | | | |
|---|---|--|
| <input type="checkbox"/> Alpine skiing | <input type="checkbox"/> Figure skating | <input type="checkbox"/> Snowboarding |
| <input type="checkbox"/> Athletics | <input type="checkbox"/> Floor hockey | <input type="checkbox"/> Snowshoeing |
| <input type="checkbox"/> Aquatics | <input type="checkbox"/> Football | <input type="checkbox"/> Soccer |
| <input type="checkbox"/> Badminton | <input type="checkbox"/> Golf | <input type="checkbox"/> Softball |
| <input type="checkbox"/> Basketball | <input type="checkbox"/> Gymnastics | <input type="checkbox"/> Speed skating |
| <input type="checkbox"/> Bocce | <input type="checkbox"/> Judo | <input type="checkbox"/> Table tennis |
| <input type="checkbox"/> Bowling | <input type="checkbox"/> MATP | <input type="checkbox"/> Team handball |
| <input type="checkbox"/> X-country skiing | <input type="checkbox"/> Power lifting | <input type="checkbox"/> Tennis |
| <input type="checkbox"/> Cycling | <input type="checkbox"/> Roller skating | <input type="checkbox"/> Volleyball |
| <input type="checkbox"/> Equestrian | <input type="checkbox"/> Sailing | |

18. Has he/she ever participated in Unified Sports?

(A Unified Sports team has players with and without intellectual disabilities who train and compete together in Special Olympics.)

- Yes, currently
 Yes, but not any more
 No → **SKIP TO 19**

a. Who are/were his/her Unified partners?

b. How was that experience?

19. In an average week, about how much time does [ATHLETE] spend in Special Olympics-related activities (i.e., training/competing)? (hours/week)

20. Has [ATHLETE] participated in a Special Olympics competition?

Yes No

21. What is the highest level at which [ATHLETE] has competed in Special Olympics?

- Local (school or city) level
- Regional / state level
- National level
- World level

22. Do you think that [ATHLETE] has benefited from his/her involvement in Special Olympics?

How? **[probe for examples, illustrative stories]**

23. Are there any other benefits that you think s/he's gotten from Special Olympics?
[probe for examples, illustrative stories]

24. Has [ATHLETE]'s involvement in Special Olympics influenced your expectations for him/her? **[probe for examples, illustrative stories]**

FAMILY INVOLVEMENT

25. Has anyone in your family attended [ATHLETE]'s training sessions and/or competitions?

[IF YES] Who? How Often?

a. Competitions?

Who?

How often?

	Always	Most of the time	Once in a while	Never

b. Training sessions?

Who?

How often?

	Always	Most of the time	Once in a while	Never

26. Have you or other members of your family been involved in Special Olympics in any other way, for example as a coach, volunteer, or member of the Family Action Network? [ASK OPEN-ENDED AND CODE]

	Who?	EXAMPLES/Comments
Coached		
Played in Special Olympics as a Unified Partner		
Participated in the Athlete Leadership Program		
Participated in the Family Support Network		
Assisted in fundraising, publicity, or recruitment activities		
Participated in some other way (e.g., volunteered for team or local program) specify:		

27. What have you and your family gotten out of this involvement [REFER TO TYPE / LEVEL OF INVOLVEMENT, whether as a spectator or involved at a higher level]? **[PROBE FOR MEANING FOR DIFFERENT FAMILY MEMBERS – I.E., FATHERS, SIBLINGS, BUT IF ALREADY ADDRESSED, DO NOT ASK AGAIN]**

28. Has Special Olympicshad any impact on the amount of time you spend together as a family?

[IF YES] Would you say it's had some impact or a lot of impact?

None	Some	A Lot
(1)	(2)	(3)

a. In what ways?

29. Has Special Olympicshad any impact on the types of activities you do together? **[IF YES]** Would you say it's had some impact or a lot of impact?

None	Some	A Lot
(1)	(2)	(3)

a. In what ways?

30. Has Special Olympics had any impact on your social relationships outside the family?

[IF CLARIFICATION IS NEEDED – For example, have you developed relationships with other athlete's families?]

None	Some	A Lot
(1)	(2)	(3)

a. In what ways?

Great, thank you. We are almost done. I just have a few more quick questions about [ATHLETE] and your family.

SCHOOL / EMPLOYMENT / DEMOGRAPHICS

31. **[IF ATHLETE IS AGE 21 OR YOUNGER]** Does [ATHLETE] attend school?

- Yes
 No → **[IF 18 OR OVER, SKIP TO 32]**
[IF UNDER 18, SKIP TO 35]

a. **IF IN SCHOOL**, what kind of school does (he/she) attend?
[OPEN-ENDED—CODE BELOW; ask questions if needed to clarify]

- Public elementary school
 Public middle school
 Public high school
 A vocational/technical school
 A special school for children/adolescents with intellectual disabilities
 Other (please specify): _____

b. Is the majority of his/her school day spent in a special education environment or in a general education or inclusive environment? **[Probe for a brief description]**

→ **SKIP TO 35**

32. **[IF NOT IN SCHOOL AND AGE 18 OR OVER]** Does [ATHLETE] have a paid or volunteer job?

- Yes, paid
 Yes, volunteer
 No → **[SKIP TO 35]**

a. What does s/he do?

b. **[Probe for type of employment – i.e., whether employment is supported or not. This may be apparent from job description. If not ask whether athlete has a job coach or works in sheltered employment]**

- Competitive employment (i.e., no supports, no coach, etc.)
 In supported employment (i.e., has a job coach)

In a sheltered workshop

c. Does s/he work full-time or part-time?

Full-time

Part-time

d. **If part-time**, brief description of work schedule:
(i.e., how many days and hours per week does athlete work?)

e. **If athlete works 3 or fewer days/ week**, what does s/he do on days when not working (brief description)?

f. How long has athlete been employed in his/her current job(s)?
(Ask open ended and code actual number of months/years)

Less than 6 months

6 months to less than 1 year

1 year to less than 2 years

2 years to less than 5 years

5 years or more

→ **SKIP TO 35**

33. **[IF NOT CURRENTLY WORKING]** Has [ATHLETE] ever worked in a paid job?

Yes

No → **SKIP TO 34**

a. **IF YES**, can you tell me a little bit about his/her work history / experience?

→ **SKIP TO 35**

34. **[IF NOT IN SCHOOL OR WORKING]** Briefly describe what s/he does on a typical day?

35. Is [ATHLETE] involved in any other sport, recreational, or enrichment programs (outside of school or work)?

- Yes
 No

a. **IF YES**, What are they?

36. What is the nature of [ATHLETE]'s disability?

37. Do you know the score of [ATHLETE]'s most recent cognitive evaluation or IQ test?

[IF PARENT IS HESITANT OR ASKS WHY THIS INFORMATION IS NEEDED - Reiterate that it is their choice to answer a question or not. Assure them we will not use this information to describe their child individually, only to describe the participants as a group. People with intellectual disabilities vary a great deal, and these scores give us an idea of their functional level.]

SCORE: _____

38. How do you describe your family's racial and/or ethnic background?

39. Which of the following represents your total yearly household income?

[READ OPTIONS BELOW.]

- Less than \$25,000
 \$25,000 - \$50,000
 \$50,000 - \$75,000
 More than \$75,000

40. Those are all the questions that I have for you today. Is there anything else that you'd like to add about [ATHLETE] or about Special Olympics?

Thanks for talking with me today. As I said earlier, our goal is to talk to as many family members as possible, including [another parent, brother or sister, and the athlete – FILL IN WHATEVER FAMILY MEMBERS ARE APPROPRIATE]. These interviews are quite brief – no more than about 10 minutes each.

REMINDE THEM THAT IT'S VERY IMPORTANT TO HEAR WHAT OTHER FAMILY MEMBERS, SUCH AS SIBS AND DADS HAVE TO SAY, AS WE DON'T GET TO HEAR FROM THEM SPECIAL OLYMPICS OFTEN.

YOU CAN SHARE THE SIBLING AND/OR ATHLETE QUESTIONS AHEAD OF TIME IF PARENT INQUIRES OR SEEMS HESITANT.

ASK IF THIS IS A GOOD TIME, OR SCHEDULE A CALL BACK TIME. TRY TO ARRANGE AS MUCH AS POSSIBLE AT THIS TIME. FOR EXAMPLE, IF THE ATHLETE IS AVAILABLE, BUT THE OTHER PARENT AND SIBLING ARE NOT, SCHEDULE A CALL BACK TIME BEFORE MOVING ON TO THE ATHLETE INTERVIEW.

APPENDIX D – SECONDARY PARENT INTERVIEW

Thanks for agreeing to speak with me. My name is _____. I'm with Special Olympics and I'm calling as part of a national project to learn more about athletes and their families. Your state Special Olympics program is part of the project, and your family was randomly selected to participate. You may have seen a letter we sent recently, describing this project. We want to hear what you have to say about your family and your Special Olympics experiences. **[IF THIS IS A FATHER]** It's especially important that we get to talk with dads, as we don't always get to hear from you. I have some questions for you which will take about 10 minutes.

INFORMED CONSENT

Before we begin, I want you to know that all information will be kept anonymous. Your name will not be connected with anything you say, and I won't share what you tell me with anyone else (unless you were to tell me that you or somebody else is in danger). You may choose not to answer any question. If you have any questions or concerns about the project, I can give you a phone number to call. **[IF THEY ASK, GIVE THEM JOANNE KERSH'S NUMBER: (617) 287-7241.]** Do you have any questions?

May I record our conversation?

[IF PARENT IS HESITANT OR ASKS WHY, TELL THEM IT'S THEIR DECISION TO BE TAPED OR NOT, BUT WE'D LIKE TO TAPE IT IN ORDER TO CAPTURE EXACTLY WHAT THEY SAY IN THEIR OWN WORDS. ALSO, ADD IN SOMETHING ABOUT NOT BEING A FAST WRITER TO KEEP UP WITH WHAT THEY SAY.]

State intellectual disabilities# before continuing with interview.

1. What is your relation to [ATHLETE]?

- Mother
- Father
- Other: _____

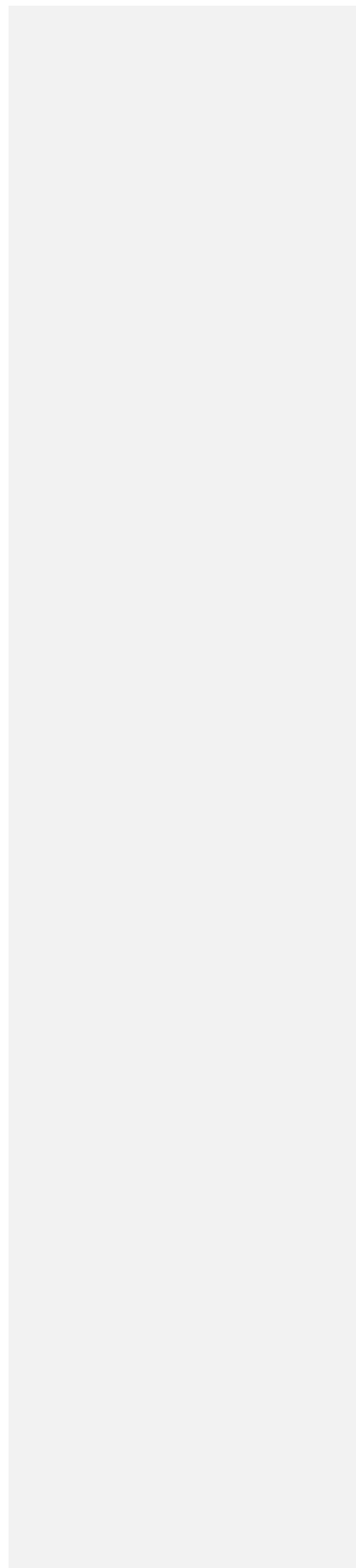
2. What are some of things that you and [ATHLETE] do together?
[Probe for one-on-one and whole family activities]

3. Describe [ATHLETE]'s strengths?

4. What would you like people to know about [ATHLETE]?

5. Can you tell me about a time when [ATHLETE] has made you proud?

6. What have you learned from being [ATHLETE]'s parent?



7. What do you think is the most challenging part of being his/her parent?

Now, I'd like to ask you some questions about Special Olympics

8. Do you think that [ATHLETE] has benefited from his/her involvement in Special Olympics?
How? **[probe for examples, illustrative stories]**

9. Are there any other benefits that you think s/he's gotten from Special Olympics?
[probe for examples, illustrative stories]

10. Has [ATHLETE]'s involvement in Special Olympics influenced your expectations for him/her? **[probe for examples, illustrative stories]**

FAMILY INVOLVEMENT

11. Do you attend [ATHLETE]’s training sessions and/or competitions?
[IF YES] How Often?

How often?

	Always	Most of the time	Once in a while	Never
a. Competitions				
b. Training sessions				

12. Have you been involved in Special Olympics in any other way, for example as a coach, volunteer, or member of the Family Action Network? **[ASK OPEN-ENDED AND CODE]**

	Who?	EXAMPLES/Comments
Coached		
Played in Special Olympics as a Unified Partner		
Participated in the Athlete Leadership Program		
Participated in the Family Support Network		
Assisted in fundraising, publicity, or recruitment activities		
Participated in some other way (e.g., volunteered for team or local program) specify:		

13. What have you gotten out of this involvement [REFER TO TYPE / LEVEL OF INVOLVEMENT, whether as a spectator or involved at a higher level]?
[IF ALREADY ADDRESSED, DO NOT ASK AGAIN]

14. Has Special Olympicshad any impact on the amount of time you spend together as a family?
[IF YES] Would you say it's had some impact or a lot of impact?

None	Some	A Lot
(1)	(2)	(3)

a. In what ways?

15. Has Special Olympicshad any impact on the types of activities you do together? **[IF YES]** Would you say it's had some impact or a lot of impact?

None	Some	A Lot
(1)	(2)	(3)

a. In what ways?

16. Has Special Olympics had any impact on your social relationships outside the family?
[IF CLARIFICATION IS NEEDED – For example, have you developed relationships with other athlete’s families?]

None
(1)

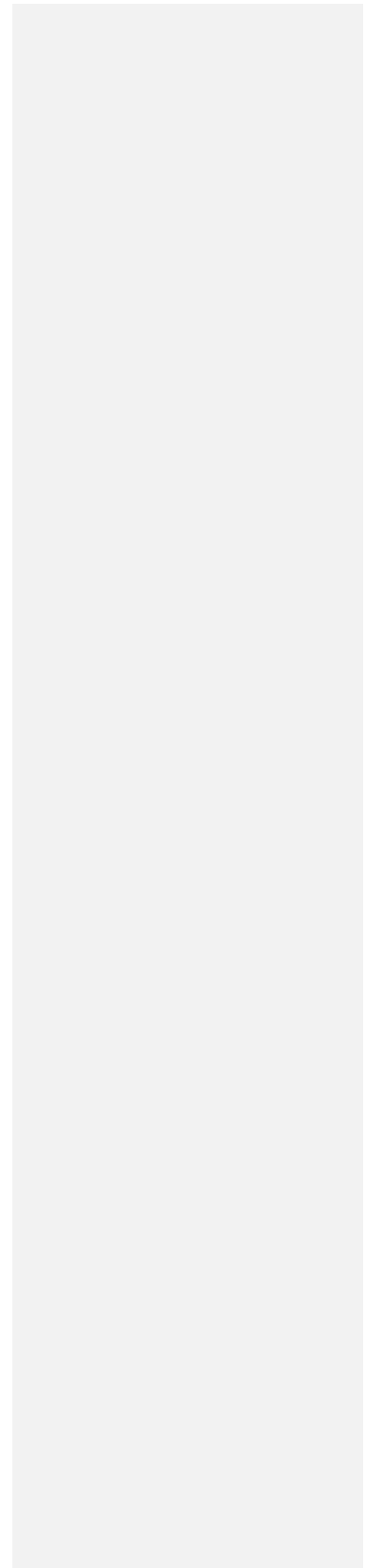
Some
(2)

A Lot
(3)

a. In what ways?

17. Those are all the questions that I have for you today. Is there anything else that you’d like to add about [ATHLETE] or about Special Olympics?

Thank you.



APPENDIX E – SIBLING INTERVIEW

Thanks for agreeing to speak with me. My name is _____. I'm with Special Olympics and am calling as part of a national study about Special Olympics athletes and their families. Your family was randomly selected to participate. It's very important to us that we get to hear from brothers and sisters as well as parents. Your [MOM / DAD] has said it is okay for me to talk to you. If you are willing to participate, I have some questions that will take about 10 minutes.

INFORMED CONSENT

[IF SIBLING IS AN ADULT]

Before we begin, I want you to know that all information will be kept anonymous. Your name will not be connected with anything you say, and I won't share what you tell me with anyone else (unless you were to tell me that you or somebody else is in danger). You may choose not to answer any question. If you have any questions or concerns about the project, I can give you a phone number to call. **[IF THEY ASK, GIVE THEM JOANNE KERSH'S NUMBER: (617) 287-7241.]** Do you have any questions?

[IF SIBLING IS A CHILD OR ADOLESCENT]

Before we start, I'd like to let you know that everything you tell me will be kept private. Your name will not be connected with anything you say, and I won't share anything you tell me with your family or anyone else (unless you were to tell me that you or somebody else is in danger). You don't have to answer any question you don't want to. There are no right or wrong answers, we just want to know a little bit about what it's like to be [ATHLETE]'s sister/brother. Do you have any questions before we start?

[FOR ALL SIBS]

PERMISSION TO TAPE RECORD

Is it ok with you if I tape our conversation?

[IF SIBLING IS HESITANT OR ASKS WHY, TELL THEM IT'S THEIR DECISION TO BE TAPED OR NOT, BUT WE'D LIKE TO TAPE IT IN ORDER TO CAPTURE EXACTLY WHAT THEY SAY IN THEIR OWN WORDS. ALSO, ADD IN SOMETHING ABOUT NOT BEING A FAST WRITER TO KEEP UP WITH WHAT THEY SAY.]

STATE intellectual disabilities# BEFORE CONTINUING WITH THE INTERVIEW

CONFIRM SIB'S NAME _____

IF SIBLING IS YOUNG ASK SOME WARM UP-QUESTIONS. -- I.E., HOW OLD ARE YOU? WHAT GRADE ARE YOU IN? DO YOU LIKE SCHOOL? WHAT DO YOU LIKE TO DO WHEN YOU'RE NOT IN SCHOOL?

1. Gender of sibling: **[DO NOT ASK; JUST CODE]**

- Male
- Female

I'd like to ask you some questions about [ATHLETE].

2. What do you and [ATHLETE] do together?

3. How much time do you and [ATHLETE] spend together? Do you do things together:

- Never
- Rarely/ hardly ever
- About once a week
- A few times a week
- Almost every day

Comments:

4. On a scale of 1-10, how much do you enjoy spending time with [ATHLETE], with 1 being not at all and 10 being a whole lot (he/she is your best friend)?

Not at all										A whole lot (you're best friends)
(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	

Comments:

5. What do you do you want people to know about [ATHLETE]?

6. Is there anything that is difficult or challenging about being [ATHLETE]'s sister/brother?
[IF SIBLING IS YOUNG, YOU CAN REPHRASE: IS THERE ANYTHING YOU DON'T LIKE ABOUT...]

7. What have you learned from [ATHLETE]?

8. What has [ATHLETE] learned from you?

Great, thank you. We're almost done. Now, I have a few questions about Special Olympics.

9. Have you gone to watch [ATHLETE] train or compete in Special Olympics sports?

- Yes
- No → **[SKIP TO 14]**

10. How often do go?

- Never
- Once in a while
- Most of the time
- Always

Comments:

11. Brothers and sisters give a lot of different reasons for why they go to Special Olympics games or meets. Why do you go?

12. What do you get out of watching [ATHLETE] participate in Special Olympics?

[PROBE FOR "MEANING" TO SIB]

[DO NOT ASK IF SIBLING HAS ALREADY ADDRESSED THIS ABOVE]

[ALSO, THIS MAY BE A DIFFICULT QUESTION FOR THE YOUNGEST SIBS – OK TO SKIP]

13. **[ASK OLDER SIBS ONLY. YOUNGER SIBS SKIP TO 14]**

Have you been involved in Special Olympics in any other way?

- Yes
 No → **[SKIP TO 14]**

a. How? **[PROBE FOR HOW AND WHY SIB BECAME INVOLVED IN THAT CAPACITY]**

b. What's been the best part of this experience for you?

c. Is there anything difficult or challenging about it?

14. Do you think SPECIAL OLYMPICS has affected your family or your relationship with [ATHLETE]?

- Yes
 No

[IF YES] How?
[Probe for descriptions/examples]

15. Do you think [ATHLETE] has changed in any way since getting involved in SPECIAL OLYMPICS?

- Yes
- I don't know / Maybe **[DO NOT OFFER AS A CHOICE]**
- No

[IF YES] How?

16. Those are all the questions that I have for you today. Is there anything else that you'd like to tell me about your brother/sister or about Special Olympics?

Thank you

IF SIBLING IS A CHILD OR ADOLESCENT, ASK TO SPEAK WITH A PARENT AGAIN

THANK PARENT AGAIN FOR THE FAMILY'S PARTICIPATION. IF YOU NEED TO TALK TO ANOTHER PARENT AND/OR WITH THE ATHLETE, ASK IF THIS IS A GOOD TIME, OR SCHEDULE A CALL BACK TIME. ASSURE THAT THE ATHLETE INTERVIEW AND THE OTHER PARENT INTERVIEW ARE QUITE BRIEF. TRY TO ARRANGE FOR BOTH IF POSSIBLE. FOR EXAMPLE, IF THE ATHLETE IS AVAILABLE, BUT THE OTHER PARENT IS NOT, SCHEDULE A CALL BACK TIME AND THEN MOVE ON TO THE ATHLETE INTERVIEW.

APPENDIX F – ATHLETE INTERVIEW

Hello, my name is _____ and I work with Special Olympics. My job is to talk to athletes and their families about Special Olympics. What you have to say is very important to us and I'm hoping you can help me out. Your [MOM / DAD] has said it is okay for me to talk to you. I have some questions about you, the kind of things you like to do, and about Special Olympics that will take about 5 minutes. There are no right or wrong answers.

Before we start, I'd like to let you know that everything you tell me will be kept private. If you don't want to answer any question, you can skip it. I won't share anything you say with your family or anybody else, unless you were to tell me that you or somebody else is in danger. OK? Do you have any questions for me?

Is it OK if I tape our conversation?

State intellectual disabilities# before continuing interview.

First I'm going to ask you some questions to help me get to know you a little better.

[YOU MAY WANT TO CHAT A LITTLE BIT TO DEVELOP RAPPORT WITH ATHLETE]

1. **[IF AGE 21 OR YOUNGER]** Do you go to school?

- Yes → **[SKIP TO 3]**
 No

2. **[IF 18 OR OLDER AND NOT IN SCHOOL]** Do you have a job?

- Yes
 No → **[SKIP TO 4]**

3. How's that going?

[REFER TO SCHOOL OR JOB]

→ SKIP TO 5

4. **[IF NOT IN SCHOOL OR WORKING]** What did you do today?

5. What kinds of things do you like to do when you're not at school / work?
[OR What else do you like to do?]

6. What kinds of things do you like to do with your family?

7. I understand that you are a Special Olympics athlete. What sports have you played in Special Olympics?

8. Does your family ever come to watch you play sports?

- Yes
- No

a. **IF YES**, who?

b. What do you think about that?

You're doing great! Just one more question to ask you.

9. What's your favorite thing about SPECIAL OLYMPICS?

**THANK ATHLETE & ASK TO SPEAK WITH PARENT AGAIN ON THE
PHONE.
THANK PARENT AND FAMILY FOR PARTICIPATION.
IF NECESSARY, SCHEDULE ANY REMAINING FAMILY MEMBERS NOT
YET INTERVIEWED.**

END