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Disability and Drowning: Personal Experiences, Research, and Practicalities of Adapted Aquatics

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One in every fifty individuals is born with a physical or intellectual disability which will potentially modify his or her life. A fulfilled life includes opportunities for swimming, sailing, boating, and other aquatic sports. There is a potential of increased risks of drowning if children born with a physical or intellectual disability participate in such water sports. These risks are potential, but ought not be realized. A mainstream responsibility (and challenge) for all involved in aquatic professions is to maximize the opportunities for aquatic experiences among individuals with disabilities without also allowing the potential risks to translate into drowning or other serious injuries. Three key themes for the inclusion of individual children and adults with disabilities are "respect, relationships, and opportunity." In this paper, we describe experiences with adapted aquatics for children with uncontrolled epilepsy and other disabilities who nevertheless can participate in aquatic experiences and sports with vigor, yet with safety. Our personal experience of children who do not meet traditional safety criteria is such that aquatic participation is still possible with extra supervisory provision.

Keywords: disabilities, adapted aquatics, drowning, child safety

One in every fifty individuals is born with a physical or intellectual disability which will potentially modify his or her life. One in every 100 children has epilepsy. One in 300 is born with a congenital heart lesion. One in 500 has some degree of cerebral palsy and one in 3000 has a progressive or nonprogressive form of paralyzing neuromuscular disease.

The quality of life of children with disabilities along with that of their families depends not only on the physical and clinical consequences of their diagnosis, but on societal responses to it (Harris, 2000). The first type of consequences is sometimes described as the "medical model of disability." The second set as the "social conception of disability" (Newell, 1999). In this latter view, the significant consequences of disability are social rather than physical. In this view, "the basis

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of disability is located in social conditions" (Reindal, 2000). Doctors and therapists tend to adopt the "medical model" of disability, whereas both children and adults with a disability prefer a "social model" (Reindal, 2000).

Whatever view of disability one takes, all would wish that life would be as enriched as possible and that children in particular would have opportunities for participation in sports, adventures, and pastimes without discrimination, albeit with special attention to safety. In his paper, "The social nature of disability, disease and genetics," Christopher Newell quoted a comment by a woman with a neural tube defect:

> If I lived in a society where being in a wheelchair was no more remarkable than wearing glasses and if the community was completely accepting and accessible, my disability would be an inconvenience and not much more than that. It is society which handicaps me, far more seriously and completely than the fact that I have spina bifida. (Newell, 1999, p. 172)

There exist exemplars of successful endeavors to reduce sporting and recreational discrimination against children with disabilities. In Australia, Horse Riding for the Disabled, Scout camps, Aquafins, Burns Camps, and *Young Endeavor* blue water sailing are such examples. Water involvement has much to offer children with disabilities, whether through hydrotherapy as a domain within physiotherapy or aquatic therapy (following Halliwick, Bad Ragaz, Ai Chu or other therapeutic modalities; Grosse, 2009; Tirosh, Katz-Leurer, & Getz, 2008) or adapted aquatics for pleasure and recreation. Aquatic therapy is a *centrum* of rehabilitation for children with both intellectual and neurological impairments (Becker & Cole, 2004; Tirosh, et al., 2008), especially those with cerebral palsy (Hurvitz, Leonard, Ayyanger, & Nelson, 2003). Many programs are based on the 10-point sequential Halliwick Method of integration in which a physically weak child can safely enjoy the water domain (Lambeck & Stanat, 2001a, 2001b).

In contrast to therapy and rehabilitation, water play, swimming for recreation, and competitive water sports can be important for children's development of all abilities. Aquatic experiences are one of the universals of the developmental experience of able-bodied children. Safety concerns are very important in this context, especially in children with uncontrolled epilepsy and in those with neuromuscular disease and some types of congenital heart disease.

In this paper, we explore some issues and share some experiences relevant to the aquatic domain, which may be helpful to those who advocate for a less discriminatory world for children with disabilities. An enriched life comes from experiencing thrills consequent with apparent risks—but risks that are prevented from being realized because of the implementation of overarching safety systems.

Buoyancy and the Body

Hydrostatic principles associated with the aquatic environment can lead to an apparent loss of load on muscles and thus to a reduction of effort required to activate movement against gravity (Getz, Hutzler, & Vermeer, 2006). At the same time as balancing gravitational forces, the impact of the buoyancy effect is reduced by

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the increased viscosity of water compared with that of air. The viscosity of water increases isokinetic resistance in all movement vectors, a property which can be exploited for muscle strengthening. Viscosity slows movement while buoyancy supports the body. This combination of buoyancy and viscosity can facilitate the acquisition of balance skills (Anderson & Fishback, 2010; Geigle, Cheek, Gould, Hunt, & Shafiq, 1977). These properties of water in turn can be recruited as a therapeutic intervention, rehabilitation, or recreation and can help patients particularly with acquired diseases such as neuropathic or myopathic weakness and those afflicted with joint pathology (Weigenfeld-Lahav, Hutzler, Roth, & Hadar-Frumer, 2007).

When an individual enters the water, a series of autonomic reflexes are rapidly triggered (Ferretti & Costa, 2003). A significant shift in blood from the extremities to the thorax occurs when the Mammalian diving reflex comes into play. Such effects are influenced by both temperature and age, being most marked in young mammals such as infants immersed in cold water (Hildenbrand, Becker, Whitcomb, & Sanders, 2010). In the diving reflex, triggered in humans particularly by face immersion, initial bradycardia occurs. This may sometimes lead to dysrhythmic beats, even in able-bodied elite swimmers (Ferrigno et al., 1991).

Everyone's buoyancy is different (Grosse, 2010). This fact is particularly relevant to those who supervise aquatics for both children and adults with disabilities. Many children with congenital or genetic syndromes have body proportions that differ from those of their able-bodied peers. Obesity may be a feature, either genetic as in the case of the Prader-Willi syndrome or acquired from excessive caloric intake. A low body-mass index (BMI) is a feature of Marfan's syndrome and its many variants. Similarly, the crown-pubis: pubis-heel length ratio is reduced in boys with Klinefelter's syndrome.

The forces that act on the body of an immersed person are influenced by the interplay between the center of gravity and center of moment (buoyancy). The linear difference between these two points determines rotational forces acting on the immersed body in the vertical plane. These points and the distance between them vary from individual to individual and from posture to posture. This vector may differ significantly from the norm in children with dysmorphic bodies. These factors together with differences in individual buoyancy due to body composition make each child's water dynamics unique and specific. For this reason, at least initially, it is essential that each child with disabilities has one-on-one contact and supervision with an instructor in the water until the swimmer can achieve buoyancy independence while sustaining the mouth and nose clear of the surface (Grosse, 2010; Reid, 1975).

Safety Issues

The central theme of adapted aquatics is the absolute requirement of extra attention given to safety. The basis of this approach is the adage of all injury-prevention work: "Safety is not the enemy of adventure, but an indispensible ally." Aphorism: Royal Parachute School, Royal Air Force, United Kingdom. Used in basic parachute training.

To achieve a full and rich life, children learn from experiences. Those experiences involve the challenge and thrill of perceived risk, yet never its actual

realization. The record of safety within adapted aquatics for children with disabilities is excellent. Realized harm is very rare. The experience of one of us (JP) who has cared for children with epilepsy illustrates this point. In the Brisbane Drowning Study, a total population study of 135 consecutive child drowning deaths revealed that eight of those children's deaths were associated with convulsive seizures. All of those occurred, however, in otherwise able-bodied children and none had a history of epilepsy. None was being supervised at the time of his or her death (Pearn, 1977). In another Sydney program of adapted aquatics for children with uncontrolled epilepsy with one-on-one supervision, rare seizures occurred in the water, but immediate extraction occurred and the children recovered from the seizure at pool-side without any clinical signs of immersion or subsequent symptoms (Barrie, 1981).

In spite of this excellent record of safety, the provision of swimming opportunities for children with epilepsy remains controversial for some (Neville, 1977), but we emphasize that harm, the result of realized risks in adapted aquatic programs, is extremely rare, if such occur at all. This excellent safety record has been achieved by close clinical monitoring of children with epilepsy and encouraging such children with measured effective blood levels of antiepileptic drugs who have been seizure free for a year or more to swim with confidence, albeit with full supervision. This excellent safety record has been achieved by an understanding of the trigger mechanisms that may provoke an epileptic seizure. Water itself sometimes will trigger epilepsy via the so-called "bath-epilepsy" response (Nechay & Stephenson, 2009; Pearn, 1977). Light shimmering on rippled water surfaces may trigger seizures, as may startle effects during horseplay in and around swimming pools.

Twenty years of experience of the supervision of the Superfins Western Australian program, called "Swimming for People with Disability, Fun, Fitness, Friendship" (Superfins WA Inc, 2011), reveals that children and adolescents with epilepsy can swim safely. Supervisors report that some adolescents with epilepsy in the Superfins Club have a premonitory aura of an impending seizure and are able to move to the pool-side and secure a hand-hold before an absence or seizure occurs. At least two supervisors monitor such swimmers in the water at all times and no untoward incidents have occurred among the 250 children and adolescents with disabilities participating in regular swimming programs over twenty years (P. Jose, personal communication, April 2011).

Issues of safety, paramount in the context of epilepsy and adapted aquatics, are the same for swimmers with all types of disability. Children with Down's syndrome, autism, intellectual disability, cerebral palsy, rheumatoid arthritis, congenital and acquired skeletal malformations, burns and trauma victims all can swim with safety if a planned and dedicated approach to adapted aquatics is followed. Adapted aquatics should include skilled swimming instruction by qualified teachers, especially those skilled in the Halliwick Method or related programs in the case of children with severe disabilities. Such safety practices include extra pool-side supervision for children in the water by those who know the children personally. Our experience is that a minimal ratio of one pool-side supervisor to eight children is required. In some cases one-to-one supervision is necessary, with the supervisor in the water with the child. An overall supervising qualified life-guard on duty is also essential. If such safety features are integral to an adapted aquatic program, all children can regularly enjoy the enrichment of the aquatic experience with confidence.

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Discussion

Children with congenital or acquired disabilities can so easily be denied the pleasurable experiences and sources of satisfaction that their able-bodied peers enjoy. This denial results from their principal disability. If societal limitations or exclusions are added to these disabilities, then the denial of personal fulfillment may be worse than the disabilities themselves. The majority of children and adults with disabilities prefer a "social model of disability" because the "medical model" does not help them sufficiently:

> They want to [live and work within] things that can be changed . . . they are not operating with a model of disability; they are operating with a view about how to remedy some of the evil consequences of having a disability. (Harris, 2000, p. 99)

Aquatics as a life-enriching experience can take many forms. The buoyancy of water and the sense of subjective weightlessness is enriching for children who are physically weak or paralyzed by neuromuscular disease. For others, the acquisition of swimming skills promotes a feeling of equality in those to whom equality of achievement is so often denied. For many children with disabilities, swimming stroke development, distance swimming (including ocean events) and competitions at state, national and international levels can enrich life in the same way that such participation gives fulfillment to their able-bodied peers. Disabled Sports Associations, World Down's Syndrome Sporting Championships, and Multiclass Events (formerly termed MultiDisability Events) in national titles in many countries offer such opportunities for personal fulfillment and self-respect.

Perhaps most important of all, the opening of the aquatic environment for all children and adolescents, irrespective of physical or intellectual ability, often leads to improved social and collegiate networking. The expanded opportunities of adapted aquatics often develop an expanded and enriched social network. This network is primarily composed of peers with disabilities but also it can involve an extended circle of families and able-bodied friends. As a result of the influence of aquatics for individuals with disabilities, life is enriched for all.

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