

Lifespire:

A Story of Advocacy



*and How a Small Group of Parents
Changed the World*

Kevin Rice

Foreword

The story of Parents Association for C.R.M.D.¹, now Lifespire, is a family story. It is the story of kitchen table conferences where activist parents met to develop a "recipe" of visions and plans to provide for the future of their disabled children. It is an archetypal story of the virtues of homegrown efforts directed to a parent's most exquisite and painful personal challenge—providing lifetime care for a vulnerable child in a world that has all too frequently been hostile to the disabled.

The story of ACRMD, faithfully told in this remarkable history by Kevin Rice, bears witness to the tangible and unconditional expression of love and care many parents had and have for their children. Love and care, nothing more or less, was the motivating force behind these parents' collective efforts.

In the late 1940's, when Ida Rappaport and Harry Kamish were confronted with providing for their children with special needs, there was little help from the community or government. The schools cast children out once they were teenagers. For many disabled children, what existed beyond school was a terrifying void.

In their desire to address these grave concerns, Ida and Harry turned out to be talented organizers. They each made a career in challenging government to fulfill its social obligation to provide for children. From humble beginnings, these extraordinary parents extended their personal campaign into fierce advocacy for every child that needed care. They were joined by many parents whose fight to secure care for their own children served the broader struggle for all children and adults with disabilities. This recipe for advocacy has survived: today's parents and their children are the beneficiaries of this legacy.

Some of the parents connected to the original parent-advocates still serve today on the Lifespire Board of Directors. Larry Hirsch and Jerome Greene who, along with their beloved family members, worked relentlessly to secure a safe place and a decent life for their respective children, are living examples of the power parents have to forge a community of care from a community of neglect. Their model of success in the face of adversity breathes life into the organization every day and Lifespire continues to move forward as a vibrant affirmation for our children. It has always been far more than a mere bureaucracy.

A new generation—the siblings of our "consumers" and even Ida Rappaport's son, self-advocate Michael Rappaport—serves on the Lifespire Board of Directors and continues the tradition of advocating for our loved ones.

Ellen Greene and the late Linda Cohen also continued the struggle for their brothers and sisters. Today, a dedicated collective of parents and committed professionals guide Lifespire's efforts.

Lifespire, in the end, has become nothing less than a paradigm showing families how to build a network of love and support for their family members. It is an ongoing success story in the campaign for parent advocacy. Armed with the generosity, service and commitment of concerned individuals from all walks of life, families constructed the community of protection that separates our vulnerable loved ones from cold institutionalization or, worse, the all too common abuse and dehumanization which shamefully continue to occur in institutional settings.

The nightmares that afflict the disabled are brutal to confront but also serve as deeper motivations to accomplish what is necessary, what is humane, what is safe. I know that my uncle, Harry Kamish, experienced profound worry about what would become of his son. This intense concern is what, in part, moved him, Ida Rappaport, and later Mickey Marlib and many others to work so hard to shield their children from feared outcomes.

The outcome of these efforts was heroic, even if unsung. My cousin, Eugene Kamish—whose serious cognitive deficits were countered by his abilities (the archaic term “mentally retarded” was a regrettable disservice to him and so many others)—had a home with Lifespire that was his castle until the day he died. He worked for more than three decades at a job he didn't always love but which was a source of productivity and pride. He earned money. He had savings. He contributed. He had someone who watched out for him. He was cared for and, as the ultimate fulfillment of his parents' hopes and dreams, he had a good life. Quite remarkably, he cared for his mother when she was in need.

Eugene Kamish's experience continues to be replicated in the lives of many other individuals served by Lifespire.

Tragically, the numbers of children who require care has exploded in the last two decades. The battle for supports for those children was won, in part, in the 1970's with the enactment of the Individual with Disabilities Education Act. Due to hard fought community battles and legal victories, the worst abuses seen in government warehouses for the disabled (like the infamous Willowbrook) were addressed. Enlightened care for individuals with disabilities seemed at last a possibility.

As with Ida's and Harry's kids, the children afflicted in the last two decades will need care as adults. But how will we care for such an enormous cohort of children who are rapidly coming of age? Financial and political stresses will always operate to erode the progress achieved by Ida's and Harry's generation and the challenges facing us today are as great as they ever were for them.

Lifespire is an historical object lesson of how motivated parents, in partnership with skilled professionals and a dedicated corps of direct support workers,

can provide a high level of care for their children. With varying degrees of success, government funding for adults provides lifetime care for many, though the new generation of children needing care for life threatens to exhaust available resources. There is the looming fear—far too often realized—that the level of care will recede and new horror stories of abuse and neglect will emerge. The suffering could be palpable and our worst projections realized unless we continue our efforts. Fortunately, today, for the most part there is competent, responsible care for our children committed, well-trained, direct care professionals in whom we can place our trust.

Parents have shown that, through organization and persistence, they can provide the chance for good lives for their children. We, as parents, must be ever vigilant to cultivate our individual and collective power so that our children may be nurtured by our society and their lives enriched and made secure. It is for the good of our society as well. As Ghandi and others have stated, there is no greater measure of a society than how it treats its weakest members. And perhaps there is no greater harbinger of social disintegration than the erosion of care for the most vulnerable among us.

The book authentically recounts the image of Harry Kamish and hundreds of parents blowing whistles (all supplied by ACRMD's Micky Marlib) on the street outside the windows of legislators. The image serves as an emblem for successful advocacy, illustrating how mundane tools, like the proverbial slingshot, can empower the powerless.

The stories told in this book are the legacy of Lifespire. Its tale of fighting the odds for civil rights and essential care for disabled children is as critically important to our community as any heroic struggle in our nation's history. Though parents today might face challenges that sometimes differ from what Ida and Harry once confronted, the accounts in this book may still serve as a compass, one that has remained true over time. The story of the parents who created ACRMD, now Lifespire, is the best inspiration for action. It must be told far and wide so that committed parent-advocates may learn to effectively fight new battles for the sake of their loved ones.

Our beloved children deserve nothing less.

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¹ Parents Association for C.R.M.D. was the original name for the Association for Children With Retarded Mental Development or ACRMD. In 2001 the organization's name was changed to Lifespire.