

From Darkness the Dawn

How Beit Issie Shapiro Changed
the World of Disabilities in Israel

Naomi Stuchiner ● Israel Sykes ● Sharon Bacher

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בֵּית אַיִשְׁיָה שָׁפִירָא
לשוני באנט חילום של אנשים עם מוגבלויות
Beit Issie Shapiro
Changing the lives of people with disabilities
בקמפוס וויל וסיליה טראומט
On the Willie & Celia Trump Campus

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Dedicated to the thousands of people throughout the world, who have brought hope
to the lives of Israeli children with developmental disabilities and their families.

You have helped us turn their Darkness into a new Dawn.

גַם־חֹשֶׁךְ, לֹא־יִחָשֵׁךְ מִפְנָךְ;
וּלְילָה, כַּיּוֹם יָאִיר — -- פְּחַשִּׁיכָה, פָּאוֹרָה

(תהלים קל"ט, י"ב)

Even the darkness is not too dark for Thee,
but the night shineth as the day; the darkness is even as the light

(Psalms, 139, 12)

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Authors' Personal "Thank You"

Naomi Stuchiner

I had the privilege of growing up in a family in which giving to and helping others was part of my life.

My brother Max, my sister Esther and I were brought up to fight for the rights of those who were less privileged in society and to believe that we could make a difference. I thank them for believing in me when they placed in my hands the task of establishing and leading the venture that bears our father's name. I am proud that the legacy that we received as children has been passed on to the next generations – to our children and even grandchildren.

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Israel Sykes

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I would like to thank Naomi Stuchiner for including me in the Beit Issie Shapiro family, for our friendship in which we grew together as social entrepreneurs, and for our shared journeys of social change. It is a great privilege for me to jointly publish this book and to embark with her on the journey that will come in its wake.

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Sharon Bacher

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Preface to the English Edition

This book was first published in Hebrew (July 2011) in Israel for our Israeli audience. The base of our operations is in Israel, and this book is first and foremost a documentation of Beit Issie Shapiro's (BIS) impact upon Israeli society. The field of social entrepreneurship is relatively new in Israel, and very little literature exists in Hebrew that describes social entrepreneurship at work in our society. It was therefore important to us to publish the book first in Hebrew for our local audience.

At the same time, from its outset BIS has been an international organization, thus it was clear to us that an English version of the book was a must. Beit Issie Shapiro was founded by a South African family living in Israel in memory of their brother/husband/father (Issie Shapiro), and as you can read in part five about the "founding family", the extended family's global network was a critical factor in mobilizing the resources required for the organization's success. Over the years thousands of people in Israel and throughout the world have contributed to this success in a wide variety of ways. These people have become part of the "global Beit Issie family", they are all pieces in the Beit Issie "puzzle". It is to them that we have decided to dedicate this book.

In addition to mobilizing financial resources abroad, BIS also mobilized professional resources. It was clear at the outset that we in Israel had much to learn from professional developments in the field of developmental disabilities in other parts of the world - where institutions were already being downsized, services were being developed in the community, and children with developmental disabilities were learning in inclusive environments. We learned from advances in research, training, practice and legislation. We learned to speak a new language. In innumerable ways we applied what we learned in our own practice, often, as in the case of the Snoezelen, developing it in unforeseen directions. With the passage of time we began to notice that our relations with our international partners were shifting. We began to give back to the professional community - through collaborations and trainings, through site visits in our center, through publication in international journals, and through our international conferences.

The English version of this book is being finished at a time of major change in Israeli society. The past summer saw demonstrations of unprecedented size calling

for "social justice", with a new generation of leaders emerging from the working middle class and demanding that Israeli society refashion its values and priorities. While of course there is no direct correlation between these protests and BIS, it appears that the values of human dignity and social responsibility that we (and other organizations in the civil sector) have been promoting for so many years have taken root in this younger generation. While it is too early to know how the protest movement will affect Israel's future, we look on at this development with pride and amazement, and will do our best in the coming years to nurture this newborn hope for a better future.

Writing this book has given us, and hopefully our readers, a new perspective on both the very real changes that have taken place in the field of developmental disabilities in Israel, and the distance we still have to go. One of the signposts of this change was reflected in the language used to describe the people whom we serve. In previously published articles included in the book and in statements made by interviewees or seminar participants, the words "mentally retarded" and "mental retardation" were used. In most cases we replaced these with the phrases "intellectual disabilities", or "people with intellectual disabilities"; in a few others we left the original language but put it in quotation marks. At the same time, when referring to governmental agencies, we did not change official names.

If the history of Beit Issie Shapiro's impact on the field of disabilities in Israel is like a puzzle, then every piece reflects a partnership built over time: with children and adults with special vulnerabilities and needs; with parents and extended families who contributed their insights, articulated their needs and became effective advocates for change; with professionals who developed their skills and devoted their lives to improving the opportunities of others; with governmental and semi-governmental representatives who used their offices to effect change; and with far-sighted philanthropists who use their hard-won resources to realize dreams and build a better, stronger and more compassionate society in Israel. It has taken all of us, working together, to turn the darkness into a new dawn for children with disabilities and their families.

Foreword

Transcription of Dan Senor's¹ Address at Beit Issie Shapiro's 30th Anniversary

Gala Event

November 17, 2010

This is my first trip to Israel since "Start-Up Nation" was published, since the book was released. Jean is right when she says it's the first time I've been back since the book came out. And the reason I feel so strongly about Beit Issie Shapiro is in many ways, it embodies the theme of entrepreneurship and the theme of innovation.

We hear so much about Israeli companies and we hear so much in the context of Israeli technology, you hear the data – we talked about it in our book – there are more Israeli companies listed on the NASDAQ stock exchange today than companies from any country in the world, except for China and the United States. Global venture capital, which we argue in our book, is the most fungible metric of technological promise, and yet there is more global venture capital on a per capita basis coming to Israel today than to any country in the world, including the United States: 2.5 times more than the US, 30 times more than Europe, 80 times more than China, over 300 times more than India. Those are the stories we talk about in our book, that's the data we talked about, these are the stories of companies we talk about.

But there is a entirely different world of innovation and entrepreneurship, as I said, it's social entrepreneurship – it is the work of a place like Beit Issie, which is not necessarily [technological], although there is some technological innovation. But the real innovation is how you think about solving a big problem – a big social problem. Take for example Issie Shapiro, when he decided to start working with the disabled community here in Israel, that it was critical that the disabled community

1. Co-author of "Start-Up Nation", Dan Senor, adjunct senior fellow for Middle East studies at the Council on Foreign Relations, has been involved in policy, politics, and business in the Middle East. He served as a senior foreign policy adviser to the U.S. government, a Pentagon adviser to Central Command in Qatar and as a foreign policy and communications adviser in the U.S. Senate. He studied at Harvard Business School and today is with a New York-based global investment fund. Senor's analytical pieces are frequently published by the Wall Street Journal; he has also written for the New York Times, the Washington Post, the Weekly Standard, and Time.

be fully integrated in the regular communities, and towns and cities, throughout the country. That you can't just marginalize people because of their disability and keep them on the outskirts of society. That they are actually as valuable, as important, and in their own ways, as blessed as everyone else and should be part of the community. This is an innovation.

There are many parts of the world where this is not the case – we write in our book about places like Dubai - some people often compare the economic miracle of Israel to the economic miracle of Dubai. Why? The economies are of comparable size, the population is of comparable size, they're both very globalized, people come from all over the planet to be there. But the difference between a place like Israel and Dubai, is people do come to Israel and build great enterprises, but they're also building a society. They are also building community. They are invested in the society and the country, whether the economy goes up or down. It is one of the great shock absorbers of the Israeli economy – that no matter what is going on in the country, people are here to build something bigger than themselves and bigger than their own company. And in many respects that is the greatest jolt - that sense of commitment, that is the greatest jolt to the strength of Israel's economy. And in a place like Dubai, people come there – I use Dubai as an example, but there are others too – when people come to Dubai, they come to do business, they come to make some money, then they leave. They go back to Riyadh, they go back to London, they go back to Moscow, they go back to the United States – those parts of the world are the places they really care about. They're not interested in building anything long lasting in Dubai.

And one of the great barometers of one's commitment to a society, is how people in that society, in terms of building that society, treat those who are less advantaged, those that are dealing with some kind of disability, that in many parts of the world is a source of embarrassment, a source of shame. And one of the great innovations of Issie Shapiro is to understand that it's not only about taking care of the disabled, but more importantly, it is about making sure the communities are fully integrated with those that are disabled. And I can go on with some of the other innovations, in hydrotherapy, and the work that's being done in the dental solutions in treating the developmentally-challenged, and I know a number of you who have been on this trip, have seen these first hand – and I am going to have some time tomorrow to get into these issues in our panel – but I just simply wanted to say thank you to Beit Issie for the amazing work that you do, thank you to Jules and Steph Trump who introduced me to Beit Issie and actually persuaded me to make my post-book maiden voyage to Israel with Beit Issie, as part of this trip, that many of you are on, and to thank all of you for helping make Beit Issie another example of why Israel is a model for the world.

So much of the debate about Israel today is between those who want to de-legitimize Israel and those who believe we have a moral obligation to Israel - that we in the West owe something to Israel. And there is actually a third point - obviously Israel shouldn't be de-legitimized, and obviously we in the West do owe something to Israel - but we also have something to learn from Israel. And that it's not only a one-way relationship – Israel's relationship with the world is a two-way relationship. And I don't have time to get into it tonight, but we talk a lot about this in our book – that Israel is a contributor to the advancement of humankind. Israel, whether it's in biotech or medical devices, or cleantech, or greentech, or information technology, Israel is actually - to paraphrase the name of Shai Agasi's electric car company - Israel is really making the world a better place. And that message, the degree to which Israel is helping the world become a better place, is what I believe Beit Issie, in terms of what it is doing for Israelis and what it can do to teach others around the world, is a central mission of our times.

Introduction

Naomi Stuchiner

From the time I began working in Beit Issie Shapiro (BIS) thirty years ago, it has been clear to me that the inspiration for our work is the belief held by my father, the late Issie Shapiro, in the basic right of **every** human being to live a dignified life, in the context of family and community. It was his greatest hope that his beloved state of Israel would become a "light unto the nations" by embodying this right in the opportunities it afforded its members with disabilities.

Recently, when I retired from my managerial responsibilities in BIS, I felt that the time had come to reflect upon the extent to which we had been able to live up to my father's aspirations. I decided to take a look at the achievements of the past thirty wonderful years, and to document the journey we had made together with so many fellow travelers.

I chose to formally mark my retirement by hosting a seminar that we called "Closing Circles – Thirty years of Social Entrepreneurship". This event was attended by many extraordinary people from a range of fields, all of whom I had been privileged to work with meaningfully during part or all of my thirty years at BIS. We spent an afternoon together reflecting: Where did it all begin? What really happened in Israel during these years? What have we achieved so far? And of course, what has been the role of BIS in the major changes that have taken place in Israel during these years in the field of disabilities?

This wonderful event was the impetus behind the publication of this book, which closes many circles that were opened when I and my family initiated the establishment of BIS in my father's memory thirty years ago. Now, as I move on in new directions, I am delighted to leave behind a written legacy that both documents the history of our inspiring journey and provides practical knowledge to others who would like to learn from our work as a social entrepreneurial organization. I believe that there is much to learn from what we did and accomplished, and I hope that this book will become a valued resource for expanding circles of friends, professionals, policy makers, researchers and social entrepreneurs.

In the task of writing this book I was joined by two friends and colleagues, Israel Sykes and Sharon Bacher, both of whom have long been part of my core team in BIS. Israel Sykes, himself a social entrepreneur and action researcher, has accompanied me for eighteen years as I found my way through numerous critical turning-points in BIS's development. In this

capacity Israel played a significant behind-the-scenes role in the unfolding of the story of BIS as it is described here. Sharon Bacher, a clinical social worker with an amazing capacity for conceptualization and writing, has worked beside me for over twenty years, throughout enriching BIS with her valuable input. She has written books and articles and was my partner in developing knowledge and materials for the Resource Development Department in BIS. In her last position at BIS she served as director of the International Department for Resource Development.

I owe a special thanks to Dan Senor, who was kind enough to allow us to use as a preface his opening speech at the gala event of BIS's international mission that took place as part of our 30th year celebrations. Dan has inspired thousands of enthusiastic readers of his book (with Saul Singer) *Start-Up Nation*¹, which documents the many contributions Israel has made in many technological fields. It is a great honor for us that he views Beit Issie Shapiro as an excellent example of a social entrepreneurial organization, going so far as to call it "a model for the world".

I was first exposed to the concept of social entrepreneurship in 1993, when in the context of a seminar that brought together the directors of innovative social service organizations Professor Jona Rosenfeld remarked that I stood out as a social entrepreneur. Only recently have I embraced the concept of social entrepreneurship as reflecting BIS's mode of operations. BIS moved over time from identifying a vulnerable population (children with developmental disabilities and their families) to developing and providing innovative practical solutions on a limited scale, to transforming over time the place of this population in the larger society - thereby ultimately fulfilling my father's vision of a changed and more caring Israel. It is this progression that is the underlying theme of the entire book.

The book is divided into six sections: Descriptions of BIS as a social entrepreneurial organization; case studies of innovative professional programs that developed within BIS and went on to impact services provided throughout Israel; thirty years of activity in pictures; the models of resource development implemented by BIS in Israel and throughout the world; reflections on the special roles of the founding family in the development of BIS; and a view from the past to the future.

Chapter 1, an analysis of BIS as a social entrepreneurial organization, provides the framework for the entire book. This chapter was written for the book *From Inclusion towards Full Participation: Challenges and Growth over the Life Span*² that was published just prior to BIS's fifth International Conference in July 2011. We are grateful to the editors Dr. Meir

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1. Senor, D. and Singer, S. (2010) *Start-Up Nation: The Story of Israel's Economic Miracle*, New York: Twelve.
 2. Hovav, M. and Hozmi, B. (eds.) (2011) *From Inclusion towards Full Participation: Challenges and Growth over the Life Span*, Givataim: Rotem Publishing.

Hovav and Dr. Benjamin Hozmi and to Rotem Publishing Productions for allowing us to include this chapter here.

Chapter 2 is of special significance as it describes BIS from the perspective of an earlier time in its development, just prior to its thirteenth bar-mitzvah year. This chapter, written by the late Ora Namir in collaboration with me, was first published in the book *Out from Under: Lessons from Projects for Inaptly Served Children and Families*³. We would like to thank Jona Rosenfeld and Jack Habib for their generous permission to reproduce this chapter here.

Chapter 3, the final chapter of this section, paints a fascinating portrait of BIS as it emerged in Israel Sykes's analysis of transcripts from the "closing circles" seminar. Our many partners answered our call to reflect together with us, and they provided us with a wealth of qualitative data that enabled us to learn how we were and are perceived by many of those with whom we have worked closely over the years. This chapter brings the direct testimony of many of our partners as they reflected on 30 years of activity and on BIS's role in promoting social change in the area of disabilities in Israel. It was deeply meaningful for me to have our accomplishments and contributions reflected back from so many people for whom I have such deep respect. It is my hope that in the years to come the model of social entrepreneurship that emerges from their reflections will become a widely-used resource among those interested in acting as social entrepreneurs or in researching social entrepreneurship.

The second section of the book presents some of the areas in which the combination between social entrepreneurship and professional innovation contributed to the development of new and exciting areas of knowledge and action. In chapter 4, Sharon Bacher writes about the development of the dental clinic in BIS, beginning with the identification of an unrecognized and unmet need of people with developmental disabilities to receive dental care, leading ultimately to systemic change in the accessibility of dental care to this population.

Tuvia Stuchiner, my husband and partner of forty years, has had a major impact on the field of hydrotherapy. He developed it from water therapy to hydrotherapy at high international standards for children and adults, and he turned BIS into the largest training center in the world in the field of hydrotherapy. Tuvia established and led the Israeli Hydrotherapy Organization that has played an essential role in developing and promoting relevant legislation. In chapter 5 he shares his perspective on the entrepreneurial developmental process of the BIS Hydrotherapy Center.

Chapter 6 by Michelle Shapiro documents the trailblazing development of the Snoezelen, a controlled multi-sensory room that is currently being used throughout Israel and beyond to improve functioning of a range of population groups in sensory, motor, behavior,

3. Rosenfeld, J.M. Schon, D.A. Sykes, I.J. (1995). *Out from Under: Lessons from Projects for Inaptly Served Children and Families*, Jerusalem: JDC-Brookdale Institute.

communication and learning skills. Michelle describes her professional entrepreneurial process as bringing together knowledge and professional experience with a personal process of insight, and sees the professional and personal backing of BIS as a critical factor in her success.

This chapter also was published in the book *From Inclusion towards Full Participation: Challenges and Growth over the Life Span*⁴ (published in Hebrew), we are grateful to the editors Dr. Meir Hovav and Dr. Benjamin Hozmi and to Rotem Publishing Productions for their permission to include the English version of this chapter here.

The third section is a display in pictures and in words of the history of BIS. For some readers pictures will speak louder than words, whether awakening memories or arousing the imagination. What a challenge it was for us to cover the grand scope of 30 years with 'just the right' pictures. We reviewed countless pictures, each one evoking a different memory, reminding us of people with whom we have a shared past. As is the nature of such projects, we had to let go of many pictures that were dear to us, but we hope that the final product does justice to the many wonderful people who have been part of our journey. My thanks to Sharon Bacher, Sharon Yeheskel-Oron and Ronit Birmaher Levari for their work in bringing this display to fruition.

The fourth section documents one of the core factors behind BIS's success over the years: Our ability to mobilize, both in Israel and abroad, the resources we needed in order to turn our vision into reality. Underlying all of the entrepreneurial success documented in this book was a professional model of resource development that I developed over the years and which I documented together with Sharon Bacher in an unpublished *Guide to Resource Development*⁵. Chapter 7 documents the Community Development Model of Resource Development that served as a basis for all of my resource development activities during my years at BIS, with an emphasis on its implementation in Israel. In chapter 8, I relate to the history of BIS's global fundraising efforts, and discuss some of the challenges we faced and the lessons we learned.

The fifth section of the book relates to the special role of the founding family – the immediate and extended family of the late Issie Shapiro – in the life of BIS. It opens in Chapter 9 with a short and moving statement by my daughter Orli, drawn from her address in the "Closing Circles" seminar, in which she spoke of the personal meaning she derived from her family's intensive involvement in BIS.

Chapter 10 is a qualitative study performed by Israel Sykes (who wrote the chapter together with me) at the time that I was deciding to hand over the Executive Director position

4. See note 2.

5. Bacher, S. & Stuchiner, N. (2000) Resource Development Handbook - A Practitioners 'Hands-On' Guide, unpublished document.

to my successor Jean Judes. The study, which combined an analysis of relevant literature related to family businesses and family foundations with an analysis of interviews with key members of the staff, board and family, was a pioneering exploration of the dynamics of founding family involvement in the development of a social enterprise. The study was first published in the book *From Segregation to Inclusion: People with Disabilities in the Community*⁶ and we are grateful to Meir Hovav, Pesach Gitelman and the Carmel Press for permission to reproduce the chapter here.

In Chapter 11 Sharon Bacher - from her unique perspective as partner and veteran manager of the international resource development department - describes and expands upon the special role that the extended Shapiro family has played in the life of the organization. She describes the exceptional contribution of the family to building an international network of support for BIS, and discusses the continued involvement of the third and even fourth generations in the BIS enterprise.

The final section of the book summarizes the past and opens a window to BIS's future. Professor Arie (Arik) Rimmerman has long been considered a leading researcher and teacher in the area of disabilities in Israel, an academic who brought the highest standards to the study of disabilities. He also has long been a friend of BIS. We are grateful for Arik's permission to publish in Chapter 12 the lecture he gave at the "Closing Circles" seminar, in which he provided an overview of the development of the field of disabilities in Israel, paying special attention to the role of BIS in this development.

Chapter 13 was written by my friend and colleague Jean Judes, into whose capable hands I gladly passed the baton after she had served for thirteen years as my professional director. Jean's background in community organization equipped her with the broad vision that enables her now to position BIS in the global arena. I have no doubt that she will continue to bring BIS to ever higher levels of excellence. In this final chapter Jean reflects on the challenge currently facing the organization, to preserve the entrepreneurial enthusiasm in a rapidly changing and developing context. She shares with us some of her thoughts about future directions of organizational change, both in the Israeli context and in the increasingly critical global network.

Finally, the book concludes with a reflective epilogue directed to the younger generation of social entrepreneurs. Too often stories of social entrepreneurs look "larger than life", leaving readers with the impression that similar accomplishments are beyond their reach. Feedback on the Hebrew version of the book prompted me to recall my early years in Beit Issie Shapiro, long before I could even imagine what BIS has become. In this epilogue I pay tribute to the people back then who saw my potential, believed in me, and enabled me to believe in myself.

6. Hovav, M. and Gitelman, P. (eds). (2006) *From Segregation to Inclusion: People with Disabilities in the Community*, Jerusalem: Carmel Publishing House.

I

Beit Issie Shapiro as a Social Entrepreneurial Model

The Development of Beit Issie Shapiro as a Social Entrepreneurial Process¹

Naomi Stuchiner

Introduction

Over the past thirty years since the founding of BIS I have presented the organization many thousands of times to a vast number of audiences. Each and every time I face the challenge of conveying in words the essence of this ever-changing organization. I have often found that the language used in the fields in which I operated failed to capture this essence.

Since BIS provides services, does this make us a service organization? Service provision is only a part of what we were about, one of our strategies for ensuring we build a society in which children with developmental disabilities and their families could have hope for a better future. This being so, perhaps BIS is a social change organization and essentially are we social activists? But social change organizations tend to focus exclusively on advocacy vis-à-vis the existing system, insisting that social structures are changed or individual or group needs are met, leaving the development of answers to these needs to professionals in the field. Yet BIS has done both - we have worked to change attitudes, values and laws and at the same time we have promoted social change precisely by developing new service models and training professionals. Or maybe we are a research and development organization, or perhaps we are best defined as a training organization that draws upon its practice, research, and development experience?

During most of my years at BIS I have drawn upon the language of my initial training in community social work to describe my professional activity, and on the whole this language served me well. It also served me well as a framework for guiding my resource development and fundraising activities, the fruits of which have provided the wherewithal for the growth of the organization.

1. Published in: Hovav, M., and Hozmi, B., des. (2011) From Inclusion towards Full Participation – Challenges and Growth over the Life Span, Rotem: Givataim (Published in Hebrew).

Yet, over the past few years I have increasingly come to recognize, that what we in BIS have done is indeed “out of the box” of the predominant languages used in the helping professions, including that of community social work. At the same time, our modes of operation are best captured by a relatively new concept that is gaining prominence in today's world: Social entrepreneurship.

In this article I would like to describe the development of BIS as a social entrepreneurial process. For this purpose I will present an initial definition of social entrepreneurship, what it is and how it compares to related activities, and then I will demonstrate the ways in which BIS's developmental process during its first thirty years reflects the essence of what social entrepreneurship is all about. Finally I will conclude with some thoughts about the ways in which the accomplishments of BIS in the field of developmental disabilities can be a critical resource for the future development of that field and of Israeli society in general.

Defining the Essence and Boundaries of Social Entrepreneurship

Martin and Osberg's² definition of social entrepreneurship provides a useful conceptual framework for looking at BIS as a social entrepreneurial process.

“We define social entrepreneurship as having the following three components:

1. *identifying a stable but inherently unjust equilibrium that causes the exclusion, marginalization, or suffering of a segment of humanity that lacks the financial means or political clout to achieve any transformative benefit on its own;*
2. *identifying an opportunity in this unjust equilibrium, developing a social value proposition, and bringing to bear inspiration, creativity, direct action, courage and fortitude, thereby challenging the stable state's hegemony; and*
3. *forging a new, stable equilibrium that releases trapped potential or alleviates the suffering of the targeted group, and through imitation and the creation of a stable ecosystem around the new equilibrium ensuring a better future for the targeted group and even society at large.”*

2. Martin, R. L., & Osberg, S. (2007) Social Entrepreneurship: The Case for Definition. Stanford Social Innovation Review (spring) pp. 35

Social entrepreneurial organizations differ in important ways from organizations that focus upon social service provision or social activism. In the area of social service provision:

“a courageous and committed individual identifying an unfortunate stable equilibrium – AIDS orphans in Africa, for example – and setting up a program to address it – for example, a school for the children to ensure that they are cared for and educated. The new school would certainly help the children it services.... But unless it is designed to achieve large scale change or is so compelling as to launch limitations and replications it is not likely to lead to a new superior equilibrium. These types of social service ventures never break out of their limited frame: their impact remains constrained, their service area remains confined to a local population, and their scope is determined by whatever resources they are able to attract.³”

With regard to social activist ventures:

“The motivator of the activity is the same – an unfortunate and stable equilibrium.... What is different is the nature of the actor's action orientation. Instead of taking direct action, as the social entrepreneur would, the social activist attempts to create change through indirect action, by influencing others – governments, NGO's, consumers, workers, etc – to take action.... Successful activism can yield substantial improvements to existing systems and even result in a new equilibrium, but the strategic nature of the action is distinct in its emphasis on influence rather than on direct action.⁴”

Obviously social service or social activist ventures play an important role in a common struggle shared by many in our fields of endeavor to create a more just and humane society. We are blessed in Israel with many such organizations doing exemplary work in a wide variety of fields. For whatever reason – undoubtedly related to my own father's legacy and my community social work background and an entrepreneurial personality – I chose a different path for BIS. Only now it is clear to me that from early on I realized intuitively, that in order to transform the unacceptable realities experienced by families in Israel who had children with developmental disabilities, BIS needed to be developed as what I only recognize by hindsight as a social entrepreneurial organization.

3. Ibid., pp. 37

4. Ibid., pp. 38.

BIS's Development as a Social Entrepreneurial Process

Looking back upon the development of BIS in light of the definition by Martin and Osberg, I will divide my reflections on BIS's development as a social entrepreneurial process into four sections: the social entrepreneurial context; challenging an inherently unjust equilibrium; demonstrating the viability of an alternative reality within a limited context; forging a new reality in the broader context.

a. The Social Entrepreneurial Context

In order to understand the characterization of BIS's development by a social entrepreneurial process it is necessary to retrace our steps and reconstruct the realities that we encountered in our early years of operation. In the language of Martin and Osberg, were we in fact identifying a “stable but inherently unjust equilibrium that caused the exclusion, marginalization, or suffering of a segment of humanity that lacks the financial means or political clout to achieve any transformative benefit on its own”?

Looking back now, I can see that I began to operate in a context that in fact met this definition, with regard to the lives of children with developmental disabilities and their families. In the following section I will delineate some (by no means all) of the characteristics of the stable equilibrium that was predominant in those years, including:

- the inevitable institutionalization of children and adults with intellectual disabilities (with a subsequent absence of support for families who would prefer to keep their child at home);
- fragmentation between government agencies and professional disciplines;
- treatment approaches that failed to see the child in the family context;
- exclusion of parents from all decisions related to their child with disabilities;
- fragmented and under-developed government systems;
- professional neglect of children with intellectual disabilities;
- and the profound experience of shame experienced by many people with intellectual disabilities and their families.

The Inevitability of Institutionalization

When BIS first started operating in Herzliya in 1981, the number of children with intellectual disabilities on the waiting list for residential institutions was growing.

When it reached 770, Ora Namir, then the Minister of Welfare, proposed, as a solution, to create more out-of-home placements. In other words, she continued to operate within the assumption that institutionalization was the accepted “solution” for children with intellectual disabilities and their families, and the solution to the problem of growing waiting lists – the gap between the numbers of children with intellectual disabilities and the numbers that could be accommodated by existing institutions – was creating a disequilibrium that needed to be addressed. The solution proposed by the Minister of Welfare for restoring equilibrium was to develop more institutions. This proposed model was common throughout the world, but was in fact being re-examined in the existing system in Israel.

For us at BIS, this solution was unacceptable. In the first place, we questioned this assumption and asked ourselves whether it was a just solution and whether it in fact addressed the needs of the children and families. We began to talk to families and study what was happening to them while they waited for their child to be institutionalized. It became clear that given the right kind of support, most families would in fact prefer to keep their children at home and in the community - if only they had this option.

Treatment approaches that saw the child as separate from his/her family context

Our first start at providing services in 1981 was based on a contract with the Ministry of Welfare that stipulated that we must implement a behavior modification model directed at shaping the behaviors of children from the age of 10 with intellectual disabilities. However, it soon became clear that the behavioral model was inadequate and that in order to help meaningfully, the child had to be seen within the context of his family: parents, siblings and even grandparents. This was unheard of in Israel at the time.

By encouraging parents to share their feelings and impressions, we afforded ourselves the opportunity of direct and ongoing feedback about our services. When we listened to the families, they told us that our focus was too narrow. Subsequently we began to rebuild our services around their needs, developing a totally new model in which the child would be seen in the context of his family and even the community in which he lived. This would include developing services that would support them in their decision to raise their child at home. A primary need at the time was for early intervention services, which would provide comprehensive treatment and education for young children with developmental delays.

Exclusion of parents from all decisions related to their child with disabilities

When we began operating parents were excluded from all decisions related to their child, to such an extent that they had no input as to where in the country their child would live and they were even forbidden to examine the institution where their child was to be placed. All decisions affecting the lives of the children and their families were made by government agencies. We were even advised by government workers not to suggest to parents to visit our program before they had been through the system. This phenomenon also existed in other parts of the world.

Fragmented and underdeveloped government systems

The well-being of children with disabilities was the mandate of several different government systems – welfare, health and education. But to a large extent these different systems were not coordinated and many children fell through the cracks and were neglected. A great many children were left at home without any school placement. There were no provisions for children with “behavioral” or “psychiatric” problems. At the time, the most developed service system for children with developmental disabilities was devoted to children with intellectual disabilities. For this reason many parents of children who had other disabilities – such as autism or cerebral palsy – were advised to get their children recognized as having intellectual disabilities so that they could be put on the waiting list for institutional placement. This led to many children being served in facilities that were not suited to their real needs, for example children with autism, who did not have intellectual disabilities, were being schooled in facilities geared for those with intellectual disabilities. It can be argued that, due to a lack of other alternatives, well-intentioned professionals used this suggestion as a last resort and through a sense of despair.

Professional Fragmentation and Neglect of the Population

Another major issue we confronted was the lack of trained professionals in the field of intellectual disabilities. There were no specialized physical therapy, occupational therapy, speech therapy programs for these children. The prevailing view was that there was no point investing in these children who did not really need and could not benefit from such treatments. The kind of prejudices that existed can be seen in the case of one social work student who, after requesting to do her group work field placement with young adults with intellectual disabilities was refused permission because “one cannot do social group work with people with intellectual disabilities”.

Shame experienced by the families of people with intellectual disabilities

Over and above all of the difficulties addressed above, perhaps the most disturbing issue of life for families with children with developmental disabilities was their overwhelming sense of shame. It was as if having a child with a developmental disability meant that there was something wrong with the parents, and parents often went to great lengths to hide the child and the fact of the child's existence. People with intellectual disabilities were hidden from view in institutions, intentionally cut off from their families and communities.

The question always arises as to why people feel shame when someone in their family has a developmental disability. I personally believe that this sense of shame arises in response to the stigma that exists in society - in general terms, our society does not feel comfortable with people who are different. It seemed to me that if we could change this situation, and reach a stage where having a child with special needs became more normative, families might be freed from this sense of shame and not feel the necessity to hide this fact nor feel so isolated.

Michael Lewis, in his book, "Shame"⁵, likens the issue of intellectual disabilities to having a stigma. He says: "the stigma associated with intellectual disabilities has a powerful effect: it not only impacts on the person's sense of his spoiled identity and prompts feelings of shame and embarrassment, but also impacts on how he goes about trying to cope with his everyday life."

He then continues "our list of potential stigmas, since it reflects standards and rules, is open to change as a function of historical time and culture... and it should be clear that stigmas are in large part culturally determined..."

When we began our work in BIS, shame was almost an inevitable response to prevalent stigmas in society at the time, which had a powerful impact on the families, on professionals and on the public. I can't count the number of times I was told "no one wants to see a person with intellectual disabilities in the community".

Indeed, it was shame that left each family isolated from their extended families and their neighbors - and from other families with children with special needs. Not having a way to meet one another, they were also not able to support each other and organize to improve their situation. As a consequence, the overwhelming majority of families with children with developmental disabilities suffered, living marginalized lives or denying their connection to their institutionalized child. Though desperately unhappy, they lacked the means to change these painful social realities.

This phenomenon became a challenge to us at BIS, mobilizing us to do all we

5. Lewis, M. (1995) Shame - the Exposed Self. New York: Free Press. pp. 196-197

could to minimize the effect of stigmas on families with children with developmental disabilities by helping to change attitudes and to educate the community, starting with young children. I believe that we have been successful to a large degree and that in fact there has been a change in attitudes towards families with children with special needs, resulting in less isolation and hopefully less shame.

b. Challenging an Inherently Unjust Equilibrium

Back then I wasn't able to make a calm analysis of the situation I was discovering, but from early on I understood that in order to succeed, to "beat the system", we would need to change the system. Again and again I found myself saying "I don't agree", and "parents have a right to choose what's right for their children". It was inconceivable that the things that seemed so obvious to me were so unacceptable for people in positions of authority. People were saying "Is she mad? It isn't going to happen!"

Looking back on the early years I wonder what gave me the "chutzpa" to continually challenge what was so obvious to others, time and again defying commonly held professional positions.

I would say that there were four factors underlying my initial tenacity:

1. Memories of my father, Issie Shapiro, who fought for the rights of people with developmental disabilities to live in the community in Johannesburg, and developed exemplary services there;
2. My father's untimely death and our family's commitment to commemorate his vision for a better society in Israel;
3. My background and experience as a community social worker;
4. My own personality, especially an innate stubbornness to accept things that did not make sense and I felt were unjust and wrong.

In the following sections I will expand on the first three factors.

Memories of my father

Being brought up in the Shapiro family was an education in commitment, involvement and caring. As children we were all exposed to the development of the Selwyn Segal Hostel, the residential facility in Johannesburg which our father developed in order to serve people with intellectual and physical disabilities in the Jewish community in Johannesburg. We became a part of it. During that time, out-of-home placement was the only alternative for families of people with disabilities.

Much has been spoken and written about my father's virtues. As his daughter I am blessed with a wealth of memories of a man of vision and integrity who always treated people with developmental disabilities and their families with great dignity.

When in our earliest years we faced stiff opposition to establishing our center within the community in Herzliya, I recalled how my father faced similar demonstrations from the community in Johannesburg and how he stood up to them. Confronted by a prejudiced community which tried to prevent us from establishing a community program for people with intellectual disabilities being set up in an upper middle class neighborhood, he stood his ground and argued their case. With his example and strength to shore me up, I faced the nay-sayers in Herzliya who shouted insults at me, making me feel like I was being lynched. And I shut out the sounds of their words and kept telling myself that they were wrong and that I had to stand my ground because what I was demonstrating for was just and right.

My experiences with my father and with his triumphs in Johannesburg gave me courage to fight to change things that I could see were morally unacceptable.

There were many ways in which my father's behavior provided a model for my work in BIS:

1. He taught me to believe in what I do – and I do, with all of my heart;
2. He showed me that dreams have an important place in our world;
3. He inspired me to commit myself to my cause and to be prepared to take risks in order to achieve my goals;
4. He taught me not to be swayed by skeptics who would try to fill me with doubt;
5. He demonstrated that there are no obstacles – only challenges;
6. He was a model of leadership with integrity and honor;
7. He inspired me to always strive for excellence.⁶

The family commitment

In his later years, when my father made Aliyah, it was his explicit intention to work to change the way in which people with disabilities were treated in Israeli society. He died tragically, while on a trip to the United States to engage interest and support when he was just at the beginning of this new mission. Soon afterwards we discovered that he had written a blueprint outlining exactly his thoughts and plans.

6. Bacher, S. & Stuchiner, N. (2000) Resource Development Handbook - A Practitioners 'Hands-On' Guide, unpublished document.

Much of what he wrote was familiar to me, not only because I knew of his thoughts, but it seemed that I must have absorbed and integrated some of his vision, for I found myself using the same language in my work.

Our family, my mother, brother, and sister, had all been exposed for so many years to our father's ambition, so that it was natural for us to make the decision to continue his work and implement his vision. This was made possible by the support of our extended family, especially Willie and Celia Trump (who was my father's sister), for whom chesed and commitment to the community were integral parts of their lives. Willie was of the 'old school' in fundraising – he had a unique ability to get people to donate to his charities through his own form of direct solicitation often using humor as his tool, and always ensuring that there would be no refusals. I learnt much from his determination and belief in how people can and should be involved in philanthropy. Willie, with Celia by his side, was instrumental, not only in providing family financial support to BIS, but in setting the basis for a strong community of supporters in their community in New York and then in Florida. Their family's support has continued to the generations following where even his great-grandchildren are committed volunteers together with the rest of his family. Willie Trump was later awarded the first Chesed Award for excellence in developmental disabilities by the then Minister of Health, Mr. Yehoshua Matza in the Knesset. Since then, the Trump family has continued to provide funding for other professionals in the country to benefit from the Chesed Award, rewarding higher standards of services and recognition for excellent services in the field of disabilities.

To this day, the extended family worldwide, is part of the BIS adventure.

My own background and experience as a community social worker

My professional training in community organization at the School of Social Work at the University of Witwatersrand in South Africa provided me with the community development model, a road-map for dealing with social problems in a systematic and purposeful way. This model has shaped every developmental process and social change effort at BIS. Its method can be summarized as follows:

1. Identifying the problem
2. Assessing the needs
3. Developing goals and objectives
4. Defining what has to be done to meet these goals
5. Identifying resources needed to meet the goals
6. Assessing resources in the community – human and financial

7. Mobilizing these resources
8. Implementing a plan of action
9. Evaluation and assessment of achievements, and hopefully
10. Finding partners for the program's future implementation.

At the heart of the community organization model implemented in BIS is the creative approach to looking for untapped resources in the community. With every new challenge we begin by examining our circles of relationships, seeking out the people and organizations who can potentially be partners to generating solutions. For example, we look to our children's parents and other family members, staff, volunteers, donors, professional colleagues, like-minded professionals in the local and national government services and management.

The development of each potential partnership is always carried out according to a well-defined community development process that seeks to engage and activate people so that each partner comes to take a share of the ownership over the joint solution.

c. Demonstrating the Viability of an Alternative Reality within a Limited Context

I decided early on that the only way to begin changing the system was by creating facts on the ground and in order to achieve these goals, it would be essential to free ourselves from depending on government funding. Only with independent sources of funding would we be able to develop the kinds and quality of services that were really needed.

Table 1 below describes a range of innovative programs that BIS developed in its early years to meet needs that had previously been unrecognized and unmet. For example, BIS identified a need for therapeutic day-care programs for children under the age of 3 with special needs; we then initiated the establishment of such programs and led a coalition to improve the rights of young children. We independently funded these programs until a new, more just equilibrium was reached, when the law passed and we began receiving funding from the government.

Table 1: Programs developed within BIS & the funding sources

Program	Need	Response	Initial funding sources
Early Intervention	There were no therapeutic day-care programs for children with special needs under the age of 3 years.	BIS initiated the first therapeutic day care programs in Israel. Also led a coalition of organizations working to improve the rights of young children with special needs.	BIS with the help of private Foundations. Parents also participated, adding stress to their budgets.
Afternoon programs	No community based afternoon care was provided for children with developmental disabilities, creating additional pressures on families and making it difficult for mothers to take work outside their home.	BIS pioneered afternoon enrichment programs, affording parents time with their other children and allowing them to work outside their home.	BIS funded these programs with the help of donors.
Dental care	Children with developmental disabilities had no access to dental care in the community. There were no preventive programs and dental professionals had no specialized training or confidence to work with them. Treatment was crisis oriented, with excessive reliance on anesthesiology, and there were no orthodontic programs.	BIS established the first community dental practice exclusively for those with developmental disabilities. Subsequently undertook research and developed training programs for dental personnel, thus contributing to the field of knowledge. Expanded programs to include full dental treatment, oral hygiene screening and guidance. Breakthrough research on the adaptation of dental environment to reduce anxiety and improve patient cooperation.	BIS funded these programs with the help of donors.
Hydrotherapy	Children with intellectual disabilities had no access to trained hydro-therapists.	BIS built the first hydrotherapy pool, became the foremost hydro-therapist training facility and provided the accepted prototype for the design of therapeutic pools.	BIS funded with the help of private donors.

Program	Need	Response	Initial funding sources
Multi-sensory “Snoezelen”	Therapists looked for creative educational and treatment programs which were more successful with children with severe intellectual and other disabilities.	BIS pioneered the development of controlled multi-sensory therapy in Israel and set up first Snoezelen room.	A donor with vision subsidized the training of professionals in Israel in this method and funded research and development.
Inclusive playgrounds	Regular playgrounds were not accessible to children with special needs. This meant they were isolated socially from regular children.	BIS set up first fully integrated and accessible playground in Ra'anana, emphasizing social and physical accessibility.	Funding was entirely by BIS and its donors.
Institute for training in developmental disabilities	There was a great need for professionals from diverse disciplines to develop special skills for working with people with developmental disabilities.	BIS established the first institute for continuing education and training of professionals in the field of disabilities.	This program was funded by donors and from partial fees from student registrations.
'Chen' Youth Leadership Development	Stereotypes and stigma toward children and adults with disabilities were common throughout society. People needed to learn about disability, the rights of those with disabilities and the value of their inclusion.	A one-year youth leadership program was implemented in junior high schools, including: 1 -Education about disabilities and the rights of people with disabilities. 2 -Volunteering with people with disabilities. 3 - Encouraging youth to initiate projects that facilitate social inclusion in schools and communities.	Beit Issie Shapiro and donors.

The social entrepreneurial spirit behind these developments, could be seen early on, and has been documented in a publication called **Out from Under: Lessons from Projects for Inaptly Served Children and Families.**⁷

In 1993, I was invited to participate in a learning seminar facilitated by Professors Jona Rosenfeld and Donald Schon, who were interested in examining together with

7.

8. Rosenfeld, J. M., Schon, D .A. & Sykes, I. J. (1995) Out from Under: Lessons from

directors of projects, who provided successful services to families poorly served by traditional services, what was different about their approach.

In their analysis of the findings, the authors noted that all projects, in order to succeed, needed to establish a niche within the larger service system in which they could serve using alternative modes of practice. Four strategies were identified that differed in terms of where the projects placed themselves vis-à-vis the families, on one hand, and existing services on the other Hand. At that time (13 years after its founding) BIS was identified as one organization exemplifying the strategy of serving families through an independently funded, alternative service. In the words of the authors:

"... these projects have operated independently, mostly on the basis of private funding. The greatest advantage of this arrangement is their independence from the decision-making of government bureaucracies, many of which have no interest in making the changes in the system which implementation of such projects would require. The project directors have the freedom to create a vision for their projects, promote their vision among potential donors and, once they have obtained funding, develop a service that meets their own standards, rather than government regulations.

BIS... has made the most of this freedom to provide an environment in which innovative services for children with developmental disabilities and their families can develop and flourish. This initiative has evolved despite the reluctance of government agencies to support the work, let alone recognize or learn from it. As a result, exemplary services are being provided to many families, but the established service system has meanwhile been left relatively unaffected.

A central challenge of this strategy is obviously the need to obtain the funds required for the development and maintenance of quality services. BIS's success has been made possible by the extraordinary fundraising abilities of its director, Naomi Stuchiner, who has developed an extensive international network of donors to whom she can turn when new project ideas come up. As she puts it (in the seminar):

When people visit BIS, and are impressed by the quality of our facilities and staff, they often react by saying: "If we had the resources you have, we would do the same thing". We had no resources. It was not as if my late father left money in order for something to be set up in his memory... How did I do it? I never said I could not do something worthwhile because I didn't have funding. There is never funding. It was always a matter of there being a need we had to answer, and so how would we find the funding? And then we would find the funding.⁸"

d. Forging a New Reality in the Broader Context

The third component of Martin and Osberg's⁹ definition of social entrepreneurship is “forging a new, stable equilibrium that releases trapped potential or alleviates the suffering of the targeted group, and through imitation and the creation of a stable ecosystem around the new equilibrium ensuring a better future for the targeted group and even society at large.” If BIS had been satisfied to create high-quality services for a small segment of the population that could benefit from them, it would have remained in the realm of social services, not of social entrepreneurship.

But from its inception BIS was committed not only to providing services but also to changing society. Creating a new standard for quality was always part and parcel of a deliberate strategy of social change that incorporated the development of new service models, community development, research, training, and structural changes through promotion of new legislation and regulations. Indeed, over the years, BIS came to see itself as somewhat of a laboratory, in which innovative ideas could be tried, new services developed, new methods perfected – and once we had the confidence that what we were doing was good and valid and effective, our aim was to bring pressure to bear on the authorities to change their orientation and services and provide a model that could be replicated by others.

Figure 1 (the chamsa) presents the social change model as it was formulated in the earlier years.

The Chamsa provides a good model for understanding the five levels on which BIS intervenes. Each part is intrinsically related to the others, and in our original model could not be separated.

- providing therapeutic day-care and treatment;
- supporting, empowering and strengthening families;
- operating community programs to raise awareness and sensitivity and mobilizing involvement in activities to promote inclusion;
- engaging in research, contributing to the development of knowledge;
- and training professionals to provide high quality services.



9. Ibid., pp. 153-154.

10. See note 2

In 2010, BIS launched a new branding process based on a strategic plan devised by its management. The above five parts of the chamsa were incorporated into the new branding as follows in Figure 2 below.



In order to illustrate the systemic impact of the programs developed in BIS, table 2 shows some of the outcomes of BIS's implementation of the chamsa strategy. The table specifies, for each of the programs described in the previous table, how the services developed within BIS funded by its donors, have led to changes in the established systems. For example, in the early intervention program, the government established a mechanism to protect infants with disabilities, thus taking responsibility for the funding, and the impact became national.

Table 2: BIS's Systemic Social Impact

Program	Government Policy Mechanism Established	Current Sources of Funding	Impact
Hydrotherapy	Today Hydrotherapy is recognized by the government as a therapeutic modality for people with disabilities.	Hydrotherapy is subsidized through the Ministry of Health and the health funds.	<ul style="list-style-type: none"> - Greater appreciation of the benefits of hydrotherapy - Greater number of hydrotherapy facilities - 70 centers in Israel. - Many trained hydrotherapists working around the country. - BIS continues to promote research and train hydrotherapists.
Multi-sensory Snoezelen	"Snoezelen- multi-sensory treatment" is now recognized by the Ministry of Education.	Multi-sensory therapy is funded by the National Insurance Institute with the Ministry of Health	<ul style="list-style-type: none"> - Approximately 400 Snoezelen rooms in Israel in many different facilities. - Greater appreciation of sensory issues as a factor in quality of life of people with developmental disabilities. - Contribution to understanding the impact of the sensory environment on behavior and well-being. - Generated research in many related areas.
Inclusive playgrounds	Close to 20 municipalities have adopted our model park design and are creating similar programs.	The National Insurance Institute and private foundations collaborate with BIS to fund the creation of accessible playgrounds that teach social inclusion countrywide, where BIS serves as consultant.	BIS's pioneer work has raised the standard of recreational facilities for children and made 'accessibility' a cornerstone of development. BIS was also influential in drafting the 'Accessibility Amendment' of 2005, to the Equal Rights of Persons with Disabilities Law (1998).

Program	Government Policy Mechanism Established	Current Sources of Funding	Impact
Early Intervention	In 2000, the first Rehabilitative Day-Care Centers Law was promulgated. This has subsequently been amended and expanded to meet the needs of the families.	The Rehabilitative Day-Care Centers Law entitles all children from 6 months of age with developmental delays and disorders to appropriate early intervention and transport to a day-care center.	All young children are entitled to therapeutic day-care, funded mostly by the government through the health funds. Approximately 90 such early intervention programs exist in Israel today.
Afternoon programs	The Ministries of Welfare and Education support afternoon activities and social clubs. An extended school day is recognized for children with Autism or mental disorders, and there is a lobby to widen the scope of entitlements.	The ministries of Welfare and Education.	Reliable alternative care frees parents to work outside their homes and pursue other interests.
Dental care	Following on BIS's success in developing dental services, at least 16 more clinics have since opened across the country, with the help of the government.	Government subsidizes special treatments according to set criteria.	Marked improvement in dental resources: <ul style="list-style-type: none"> - Higher standards of dental care. - Greater attention to prevention. - Full range of treatments provided with or without anesthesia - Orthodontics and implant therapy. - Today some 16 additional clinics have been opened around the country by AKIM.

Program	Government Policy Mechanism Established	Current Sources of Funding	Impact
Institute for Continuing Education in Developmental Disabilities	Increasingly commissioned by government and non-governmental agencies to provide specialized training. Recognition of certification.	Increasingly by government and non-governmental agencies (e.g. National Insurance Institute). Private funding solicited for some courses.	Raised the standards of service in the field of disabilities. Workers in many positions that did not require special training are today expected to develop their skill and knowledge. The Institute operated a Special University for people with special learning needs.
'Chen' Youth Leadership Development	Today some 30 schools in all areas of the country and in all population sectors participate in this program.	BIS provides core funding with the participation of local agencies (schools / municipalities / Foundations).	Programs continue to develop with wider applicability. Today participants include 'youth at risk'. BIS retrospective assessment on impact found it effective in changing attitudes towards people with disabilities.

Looking to the Future

I look back with great satisfaction at BIS's accomplishments in its first 30 years. Certainly the realities we know in the field of developmental disabilities today are radically different from those that we first confronted, and while obviously these changes are the product of the good work of many individuals and organizations, I think it is by now widely recognized that BIS took a leadership role in promoting these changes.

In looking to the future, as always I see that there will always be challenges - in the area of developmental disabilities and more broadly in Israeli society - and I wonder how the social entrepreneurial model that has worked so well for BIS might leverage broader change.

If we look now in 2011 at our society, what are some of the “stable but inherently unjust equilibria that cause the exclusion, marginalization, or suffering of segments of humanity”? Where will we find the strength and the resources to challenge those who will tell us that it is impossible, or “crazy” to bring about change? What are the social entrepreneurial initiatives and organizations that are now challenging the status quo, and how might BIS’s experience be a model for them? How might the values and inspiration that I absorbed from my father impact the work of others equally determined to work towards the creation of an inclusive and more socially responsive society?

These are some of the questions I ask myself as I move toward the next phase of my own career.

I hope that others may be inspired to take the risks and meet the challenges necessary to make their dreams for a better society come true!

Beit Issie Shapiro towards its Bar-Mitzvah

Ora Namir¹ with Naomi Stuchiner

A. Formal Presentation²

Beit Issie Shapiro is a community-based center for the care of children with developmental disabilities and their families, for the training of professionals who care for them, and for the dissemination of information to families and interested individuals about how to cope with the challenge of special children in the community.

The Center is named after the late Issie Shapiro, a native of Johannesburg, South Africa who devoted his life to helping children with physical and cognitive disabilities. Issie became their protector since he understood the difficulties these children encounter daily in the modern world. He founded a special institute for people with intellectual disabilities in Johannesburg which serves as a model to this day. After immigrating to Israel, he continued his activities on behalf of people with disabilities. Following his sudden death in 1981, his family took it upon itself to continue his efforts, in his memory. Beit Issie Shapiro (BIS) is a living monument to this sensitive and energetic man and his endeavors. It fulfills his vision of serving people with disabilities in the community.

BIS is the first center of its kind in Israel, employing a multi-disciplinary staff and providing a range of services. The Center provides a variety of care, rehabilitation,

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1. Ora Namir, M.S.W., of blessed memory, was a gifted social worker and writer. Her 1999 publication "There was also Hope" (JDC-Brookdale), about her work as a young volunteer with a family living in extreme poverty in Israel, has inspired a generation of social workers in Israel.
 2. The present chapter was written in preparation for a learning seminar held by Professors Jona Rosenfeld and Donald Schon in January 1993. The chapter is structured into three sections - formal presentation, narrative, and observational data. This was the structure recommended by Donald Schon for documentation of all eight projects to be reflected upon in the seminar itself. The chapter was first published in: Rosenfeld, J.M., Schor, D.A., and Sykes, I.J. (1995) *Out From Under: Lessons From Project for Inaptly Served Children and Families*. Jerusalem: JDC – Brookdale Institute.

education, and social services for infants, children, and adults. At any one time, direct care is being provided to some 450 children and their families. A great many more individuals are helped indirectly.

BIS has achieved all this as a result of its comprehensive view of the special child in the community, its involvement of professionals from a variety of disciplines, and the initiative and pluck of its director, Naomi Stuchiner. In May 1989, Naomi Stuchiner received the Henrietta Szold Prize in Social Work. In the words of the judges: Mrs. Stuchiner exemplifies the social worker who thinks, plans, innovates, and implements. She and her multifarious ventures are both an example and a model of social work that believes in the ability of the professional to bring about social change, gain for distressed populations their due, and accord them the respect and acceptance they deserve."

The Staff

BIS has a multi-disciplinary staff of eight social workers, nine special education professionals, eight occupational therapists, five communications clinicians, three physiotherapists, three psychologists, three art and music therapists, 24 caregivers and aides, eight national service volunteers (National service is performed voluntarily by religious young women in lieu of mandatory army service), a dentist and dental technician, an optometrist, a hydro-therapist, a lifeguard and swimming instructor, and some eighty volunteers.

Funding

The Center has an annual budget of \$1.5 million, 25% from government reimbursements (from the Ministry of Labor and Social Affairs and the Ministry of Education), 15% from parents, and 60% from donations. Naomi, with a staff of six resource development personnel, directs the fundraising and travels abroad regularly for this purpose.

B. Narrative

Stages in the Development of Beit Issie Shapiro

Soon after the passing of Issie Shapiro, his family approached the Service for the Retarded at the Ministry of Welfare and expressed the desire to establish a service in his memory to help individuals with intellectual disabilities in the community. The Service for the Retarded suggested opening a day care center based on the

behaviorist model. Naomi Stuchiner recalls:

We established an Association, and within a year we had succeeded in opening the Center, despite the many obstacles that were placed in our path. The more I was told I wouldn't succeed, the more determined I became. I felt I was stepping on a lot of toes. Later these people became friends; but, at the time, they told me that the budget wouldn't suffice, and that the idea of opening a service in the community was ridiculous. They suggested I develop an institution. They thought that I was naïve and I didn't know what I was talking about. The whole process of establishing the Center was like a treasure hunt" in which no one gives you any clues, no one tells you what your rights are or what processes you must go through, as if they're just waiting there at the end to see you fall down and fail. I felt that I had to prove to everyone that it was possible to do the impossible. I've erased from my memory some of that year's hurdles. It was very painful.

By any objective standard, the speed with which the Center was established was astonishing. But after getting to know Naomi Stuchiner's attitude and way of thinking, the speed becomes understandable. Naomi Stuchiner is constantly thinking; everything interests her, everything is raw material full of potential just waiting to be made into something. And Naomi makes use of every idea and every opportunity. In the most positive, creative way, she harnesses everything imaginable in order to promote the goals of the population she represents. The different programs that have developed in and around BIS are the fruits of her and her creative staff's indefatigable inventiveness.

On July 1st 1981, one year after establishment of the Association, the Center was opened. Sixteen children entered the Center: Eight were external participants, who would be treated in the community, and eight were boarders, for whom the government was to find appropriate institutional placements. However, when the government failed to find suitable institutions for these children after a year, Naomi Stuchiner, feeling that it was unfair to raise parents' expectations in vain, decided to close the boarding unit. In addition, by this time she had decided to implement a variety of treatment methods, rather than rely solely on the original behaviorist model.

The Center continued to accept external students as a day care center for children with moderate to severe intellectual disabilities who also had behavioral problems. Children whose parents had previously had to place them in institutions because of hardships and a lack of appropriate community services could now stay at home. Naomi Stuchiner explains:

If they stay at home, what the family needs is support even after day-care hours. That's why we opened an afternoon club that lengthens the hours of treatment and provides the children with a variety of activities. The families were having a hard time coping, so we decided to provide family therapy, sibling groups, and grandparent groups. One of the things parents described as being very difficult was their being so tied to caring for their disabled child that they couldn't afford to go on vacation – so we decided to provide respite care that would enable parents to take 'time out' on the weekends or during the week from the intensive care of their disabled child.

Our special school was initially geared for children aged four to ten. But then we began to feel it was important to reach the children at an earlier age, so we decided to develop early childhood programs that would enable us to accept six-month-old infants through toddlers who were at high risk.

A methodical, consistent, dynamic process of service development accompanied the expansion of BIS: A program would be established, new needs would be identified during fieldwork, and another program would be established to meet these needs.

The Staff

A program such as at BIS cannot depend on one person alone. Bringing such an organization to a high level of functioning requires a trained and dedicated staff. In addition to direct care workers and therapists, community workers were hired to develop new models of intervention, research each new program, and verify that services are not duplicated.

Delegating responsibility to the one hundred staff members at BIS was also given a high priority. Today Naomi feels confident that she has the top people working and that each is committed to a shared vision.

Much is done at BIS to encourage staff training and initiative. Naomi Stuchiner:

I know how important it is for the staff to have the ability to grow and develop their own ideas because I have been on the other side of the fence. Too often, their initiative is suppressed because of the bureaucratic issues or stringent boundaries outside of which a staff person is not allowed to function. It does not allow for much creativity. I am determined that this shouldn't happen at BIS. Today I feel confident that I can rely on my staff to take responsibility for developing their own ideas. Travelling so frequently makes it necessary for me to feel good about everything while am away. We are blessed with the best people.

Parents as Teachers and Partners

Every service or program that is established at the Center meets specific needs that have been identified. Parents are teachers regarding a significant proportion of the needs. They point out what they need, and are full partners in all that is done for their children. They have the right to ask and scrutinize. Naomi says that she takes parents' rights for granted; to this day she doesn't understand why this is a bone of contention for other service providers. She doesn't understand why they would be angry at parents who refuse to send their children to a certain institution – as if the parents do not have the right to investigate an institution and refuse to send their children there if they think the institution is unsuitable.

Not only do bureaucratic procedures present obstacles, but they humiliate parents, denying them the right to investigate, consult, and receive information. All that is done at Beit Issie Shapiro is done with the full cooperation of parents. Naomi Stuchiner:

In order to refer a child to Beit Issie Shapiro, a social worker must intervene, and that's all right, but to use this to say a parent hasn't the right to act directly when there's a problem, without going through the social worker, is downright insulting. Of course, the social worker and parent should both be involved in the application process – but to think that the parent hasn't the right to decide? Why not?

Every parent has the right to decide how to cope with his problem. The idea that people with intellectual disabilities could be cared for in the community instead of being shunned away in institutions was unheard of. We wanted to give parents a choice, not require them to pack their children away to an institution or keep them at home all the time. We wanted parents to be able to make a choice based on options, not on a lack of options. Once, there were no options. There were no community services, there was no support. Parents were forced to send their children to institutions. I think it's the right of every parent to choose. If there are two people, one with a child with an intellectual disability and one without, should the parent of the child with an intellectual disability have to choose where to live on the basis of where there are or aren't services for his child? Why shouldn't a parent be able to choose whether or not to send his child to an institution, rather than being forced to because he has no other choice?

Going Out into the Community

All of Beit Issie Shapiro's programs were originally operated in a number of rented homes scattered throughout Raanana. At the same time, Naomi Stuchiner began

asking the Municipality of Raanana for land on which to build the Center. Naomi relates:

At one point the municipality offered us land in the industrial zone, at another they offered us some land by a slaughterhouse on the outskirts of the city. I said I would only build within the community. What will the neighbors say?"they asked. I told them they should leave the neighbors to us. We would work with the neighbors. When we finally received land in a neighborhood, the municipality asked that we build the entrance so that it would not be opposite the neighbors.

In September 1986, Naomi Stuchiner began preparing the residents of the neighborhood in which they were to build:

I hired a community worker who went from house to house mapping the 250 households in the neighborhood. She went around with a questionnaire and with information about Beit Issie Shapiro. We then built a model of entry into the community of a potentially threatening service. We checked who lived in these households. We examined their needs and their meeting places. We checked how many of them we might employ. We produced a comprehensive survey, and we also gained the acceptance and support of the neighborhood residents. In September 1987 we moved into our new quarters.

Inviting the Community into Beit Issie Shapiro

Naomi Stuchiner believed that Beit Issie Shapiro for Children with Developmental Disabilities should become part of the community:

If the special child is to be part of the community, there must be a community that will accept him as part of it. How can the community be receptive if it is ignorant? There was a need to educate the community. It's possible to do this in any number of ways: through a series of lectures, or through tours and observations – but in my opinion, the best way is through a natural, unimposed interaction. If people come to look at the Center from without, it remains observation from without. We are interested in bringing the community into Beit Issie Shapiro.

This has been accomplished through the development of outpatient clinics in Beit Issie Shapiro's Center for Family and Child Development. The Center treats children with developmental delays and relatively mild problems, including adjustment difficulties and learning disabilities. Services include consultation with a developmental pediatrician, occupational therapy, speech therapy, corrective education for the learning disabled, and family counseling and therapy.

Getting Local Authorities to Take Responsibility for Community Services for Special Populations

At BIS, special emphasis is placed on integration into the community and delegation of responsibility for community services for special populations to local authorities. One example is the story of the "Shaked A" Kindergarten. Each year about six children with mild intellectual disabilities who have been cared for at Beit Loewenstein (a rehabilitation hospital located in Raanana) reach kindergarten age. However, there were no kindergartens suitable for them. The director of the clinic at Beit Loewenstein had worked tirelessly for years to find appropriate settings for these children, but the local authorities turned a deaf ear. Naomi Stuchiner knew that the municipality was obligated to provide a kindergarten for five-year-old children. When she approached the municipality she organized the parents of the children being treated at Beit Loewenstein.

The parents demanded their rights, sending letters and making phone calls with unrelenting intensity. Beit Loewenstein pressured the authorities and Beit Issie Shapiro used all the means in its power to pressure the municipality into giving it a license to open a kindergarten for children with intellectual disabilities. Naomi reports:

We rented a building and painted it. At 10:00 p.m. on the night of August the 31st I got a phone call from the municipality saying the municipal council had granted us a license to open the kindergarten. The next day we had a kindergarten teacher; four children showed up on the first day. Until Chanukah, the municipality maintained the kindergarten in a structure rented from Beit Issie Shapiro, claiming that if it was a municipal kindergarten, there was no reason for it to "belong to" Beit Issie Shapiro. The municipality took over the kindergarten and moved it to one of its own structures. Beit Issie Shapiro continued to provide the kindergarten with special services. We financed the necessary paramedical treatments. We took some of the money from parents, and some we donated. The municipality didn't have a problem providing the kindergarten – they had a problem providing specialized care.

To this day the kindergarten is active as a municipal kindergarten for children with mild intellectual disabilities. The Ministry of Education has accepted responsibility for providing paramedical services.

Developing Auxiliary Health Services

A dental clinic was established on the initiative of three dentists who wanted to contribute something in this area. Naomi Stuchiner:

Before establishing the clinic, we conducted a survey among the families to determine the situation. Through questionnaires administered to parents, we found that 70% of the children had never been to the dentist, and that the dentists wouldn't see them. We asked dentists and clinics if they would be willing to treat these children. They said they wouldn't because they had too much work "without having to cope with children with disabilities".

We found a contributor and held a discussion evening with the dentists. We recruited many volunteers, and then the dental clinic for people with special needs opened. The clinic provides full dental treatment, including general anesthesia, for children and adults. It's run by 70 volunteer dentists and anesthesiologists.

We are also about to open an ophthalmology clinic. Children with intellectual disabilities do not have their eyes tested regularly because it is difficult to test them properly. A pediatric optometrist from South Africa with experience in testing people with intellectual disabilities approached us. This is significant, as these children have quite a few eye problems, and if you don't know whether or not a child with severe intellectual disabilities has vision problems you can try to work with him under the assumption that he can see, when perhaps he actually can't see from a certain angle.

In order to effect a change in the attitude toward providing eye tests for the entire population of children with intellectual disabilities in this country, we linked the project to a hospital. A physician from the Service for the Retarded wanted every person with intellectual disabilities to have an eye test. They suggested that I open an ophthalmology clinic at Beit Issie Shapiro for the 6,000 people with intellectual disabilities in Israel. But I'm not interested in this, because I want there to be a service at hospitals near people's homes, so they won't have to travel great distances to be tested. We intend to open a service in conjunction with the Children's Hospital in Petach Tikva in the hope that it will be a pilot project that will spawn additional ophthalmology clinics for people with intellectual disabilities at various locations throughout Israel.

Responding to Changes in the Community

BIS's ability to keep pace with the rapidly changing times is expressed in the programs it initiates:

One of the important things in developing services is that you must know what's happening. The community changes and needs change. The environment is forever dynamic. Raanana was the first city to absorb immigrants from the

former Soviet Union directly, and that has changed the face of the city. We had no idea of the extent to which that would affect the population turning to us.

The minute the Soviet immigrants arrived, we had to reexamine both our communal and fundraising needs. I had to see how I could use this to promote the care of our population. I knew that immigration would elicit donations. We established an aides' course for immigrants. It took a long time to do this, because I said I wouldn't do it without the participation of government agencies. This was indirect work with the disabled population: I want to contribute to a change in attitude in Israel. If there are more skilled professionals in the field, there will be another level of care. Most of the immigrants don't have professions appropriate for this country. We established a 14-month program that will end at the end of March. Thirty people are being trained at the Academy for Aides, and are getting on-the-job training at all of the institutions in the area. I found a private donor to give 50% and the government gave 50%; the municipality of Raanana provides transportation from Raanana to the Academy in Netanya, and I got a Foundation to give stipends to participants (who have nothing else to live off of in the meantime). I'm looking for donors who will give stipends to graduates of the course for one year on the off-chance that they don't find work during the first year after graduation.

Remaining Open to Changes in Needs

Remaining open to changing needs is a guiding principle. Naomi Stuchiner explains:

You have to constantly reexamine needs, and it's not always easy. The mother of a child with intellectual disabilities, who represented the parents of children with intellectual disabilities before Beit Issie Shapiro was established, began working at the Center after it opened. She carried the standard with the motto: Beit Issie Shapiro's contribution is to keep the family together. Her child, who was very hyperactive, was then four. When the child reached the age of 14, the father underwent very difficult heart surgery, and the mother decided she had to remove the child from the home. If I were asked what is my philosophy and the philosophy of Beit Issie Shapiro, it would be "the child in the home." That same woman came to me and asked for help in finding a setting outside the home for her son. That required a great deal of strength from her; for me, it was a moment of contemplation and truth. In effect, my task now is to help take the child out of the home. I expended a great deal of energy to find a placement for the child. Two weeks ago the child was accepted at an appropriate institution. Even now I get chills when I think about it, because on one hand we succeeded,

but on the other, it's the shattering of a dream – that the child should always be at home. For this family in particular, standard-bearers of keeping the child at home, this is especially difficult. But the motto doesn't fit every situation. Needs change in this context, too, and we must be sufficiently flexible to accept this.

Promoting Multidisciplinary Education

It was not easy at the beginning to find trained people who were willing to work with children with severe intellectual disabilities. In order to obtain such a staff, Naomi realized that BIS had to get involved in professional training. A relationship was set up with the Bob Shapell School of Social Work at Tel Aviv University which became the springboard for development of relationships with other university faculties.

Beit Issie Shapiro is currently an important center for training care professionals in fieldwork. It serves as a training site for the Bob Shapell School of Social Work at the University of Tel Aviv, the Department of Special Education of the School of Education at Tel Aviv University, the Department of Occupational Therapy and Communications Clinicians at the School of Medicine of Tel Aviv University, the Department of Rehabilitative Psychology at the School of Psychology at Bar Ilan University, the Academy of Arts in Ramat Hasharon, and the Levinsky Teacher Training Seminar. People from all over the country flock to Beit Issie Shapiro's professional library.

Beit Issie Shapiro is particularly geared to multidisciplinary training. Naomi Stuchiner explains:

At the university, students can learn different professions that deal with special populations: special education, speech therapy, occupational therapy, medicine, nursing, psychology, social work. However, these professions meet only in the field. It's important that there be training for multidisciplinary professional teamwork. If there were such training, things would be easier in the field. I still have a dream that there will be training for multidisciplinary field work at the university on an academic level. But in the meantime, responsibility falls on the field. When you're working and you care about a child, you'll look for any means possible to improve his life.

The Need for a Forum of Professionals in Israel

Naomi Stuchiner talks about the need for a forum of professionals:

I was invited to an international conference of social workers. I met administrative social workers from 30 countries – it was outstanding. I felt

good with this group of people, even though I wondered what I had in common with someone who's feeding the hungry in Kenya? But the administrative dilemmas were the same for all of us. Sometimes, in my work, I feel that no one understands me, that I'm alone. That I'm fighting for things that shouldn't be fought for. Sitting with these people did me a lot of good. I'm not the only one who's doing things in the field. People who work in the field should share with one another. How do you gather information and stay creative enough to apply that information to what you're doing? The more systems move toward privatization – since the government doesn't take responsibility – the more initiative this demands from the field, and people need to be ready for this.

There is a framed plaque on the wall in Naomi Stuchiner's office. It reads:

Do not walk ahead of me
I may not follow
Do not walk behind me
I may not lead
Walk beside me
And be my friend
(Albert Camus)

I turn to leave the office and see on the wall opposite me:

Obstacles are what you see when you take your eyes off the goal.

C. Observational Data

The observational data section is comprised of excerpts from a published booklet which describes the process of preparing neighborhood residents for the entry of Beit Issie Shapiro.

General Introduction

Locating services for special populations in the heart of residential neighborhoods often arouses the antipathy of residents, causing them to organize to prevent these services from settling in their midst. In light of this, care settings for "special"

populations are often located in isolated areas and in industrial zones on the outskirts of cities. This only reinforces the stigma associated with these populations, precludes the interaction of the special and normal populations, and creates difficulties for the populations needing access to these services.

The cumulative experience of services for special populations that have attempted to locate in residential areas (drug and alcohol rehabilitation centers, halfway houses for delinquents, hostels for the people with psychiatric and intellectual disabilities, etc) indicates that residents' hostility sometimes prevents the services from opening. Many of these services are forced to wage protracted legal battles with residents in order to realize their right to operate in their intended location.

Beit Issie Shapiro

Beit Issie Shapiro is a community treatment center for developmentally disabled children. For six years, until September 1987, Beit Issie Shapiro operated out of four rented facilities in Herzliya and Raanana. Plans were made to build a permanent structure to house all of the Center's activities. In the belief that the special child belongs in the community, it was concluded that the new Center should be located in the heart of an average residential neighborhood. The founders believed it behooved the community to learn to live with and alongside special populations.

In the past, the entry of Beit Issie Shapiro into a rented structure in a residential neighborhood in Herzliya had been greeted with enmity by neighborhood residents, who waged a protracted legal battle to prevent the Center from opening in their neighborhood. Following the "failure" of the residents' fight, the Center opened in the intended location. The reality of living in proximity and the daily contact between residents and the population being treated at Beit Issie Shapiro led the residents to a closer acquaintance with the children and changed the residents' attitudes. Some of the neighbors developed warm relationships with the children, and some even volunteered at the Center, or approached Beit Issie Shapiro for treatment of their own children.

The rationale behind the program

The experience of Beit Issie Shapiro in Herzliya, and the past experiences of similar settings, indicate that the resistance of residents is often due to ignorance about the population to be treated and stereotypes about "special" individuals.

It was clear that the entrance of Beit Issie Shapiro into its permanent home would cause a certain change in the physical and social-psychological climate of the

neighborhood, and would arouse the forces that opposed change. In light of this, the entrance of Beit Issie Shapiro into its permanent structure in the Shazar neighborhood of Raanana was prepared according to a plan whose principal components were:

1. Understanding the demographic composition of the neighborhood;
2. Understanding the balance of power in the neighborhood, identification of centers of power and the forces opposing change;
3. Examination of residents' attitudes toward Beit Issie Shapiro and of the amount of information they had on the population treated by Beit Issie Shapiro;
4. Provision of information about the population of children to be served by Beit Issie Shapiro and the character of the Center's activities;
5. Examination of the community's needs – needs that Beit Issie Shapiro, as a community treatment center, might be able to meet;
6. Addressing residents' anxiety about the effect that the location of a treatment center for "special" children in the neighborhood might have on the quality of communal life.

It was necessary to use the knowledge and skills of the community social worker to moderate as much as possible the forces opposing change and to dispel fears accompanying the change.

The plan of action

The plan of action had two principal stages:

Stage I: Meetings with municipal and community authorities;

Stage II: Meetings with residents; gathering data about the demographic composition of the neighborhood, the attitudes of residents toward the "special" children to be treated at the new Center and toward the establishment of the Center in the heart of the neighborhood, and residents' expectations from the new Center.

Implementation

Beit Issie Shapiro opened and began accepting and treating children in its new facility in Raanana at the beginning of the 1988 school year, as planned. Approximately two weeks before the opening, an access road to the Center was paved between two residential buildings. On the initiative of an opponent of the Center's presence in the neighborhood, the residents were organized and resisted the paving of the access road, claiming it would endanger the neighborhood children. In negotiations with

the neighborhood committee in which representatives of the Raanana municipality participated, it was decided not to pave the road; an alternate pathway to the center was made. The residents saw this as representative of the Center's willingness to consider their needs and as a success for their neighborhood committee.

Later, a joint Chanukah party was held for the children of the Center and of the neighborhood. Over 150 children from the neighborhood came to the party, some of them with their parents. The party was an immense success, and contributed to strengthening the relationship between the neighborhood and Beit Issie Shapiro. After meeting the children of Beit Issie Shapiro, neighborhood children began to volunteer at the Center.

An impressive opening ceremony was held for the new Center to which all the residents of the neighborhood were invited. These encounters proved that the residents had accepted the Center's presence in their neighborhood; some of them were even happy about it. By this time it was clear that it was no longer necessary to initiate activities to overcome the residents' resistance to their new neighbors. Beit Issie Shapiro, located in the heart of the neighborhood, was a fact that could be lived with and enjoyed.

Learning from Our Partners: A Thirty Years Retrospective

Israel Sykes

Introduction

On January 26th, 2011 Beit Issie Shapiro (BIS) hosted an event to formally mark Naomi Stuchiner's final handing over of the running of Beit Issie Shapiro to Jean Judes. Naomi wanted this event to go beyond the usual ceremonial marking of such occasions, and saw the transition as an opportunity to foster critical learning that could draw on the memories and reflections of those who had been important partners during the different phases of the thirty years of BIS's activity. In our joint work with Beit Issie management staff in the planning of the event we identified the following goals:

1. Providing recognition to the many people who have made significant contributions to and with BIS over the years in the field of disabilities.
2. Creating opportunities for people from different "circles" of involvement to 'see the whole picture' and understand their 'place in the puzzle'.
3. Generating a publication that documents BIS as a social entrepreneurial organization.
4. Creating opportunities for renewing old relationships and generating new collaborations.

Process

To start the learning process, Naomi identified and personally invited over 200 people, all of whom she regarded as significant partners in Beit Issie's development, to an afternoon of reminiscence and discussion entitled "Closing Circles: Thirty Years of Social Change". Invitees included parents and self advocates, professionals, staff, donors and volunteers, and representatives of academia, local government, and relevant government ministries. They were asked to note their preferences from

among the following discussion groups, each one of which was to be led by an expert in the field who was her/himself a significant catalyst for change in the field being discussed:

- Development of support services for families, facilitated by Maya Goldman¹;
- Innovations in services and treatment methods, facilitated by Israel Sykes;
- Early intervention and educational services, facilitated by Batya Hodatov Beracha²;
- The community as the starting point for change, facilitated by Dr. Shimshon Neikrug³;
- Developing professionalism in the field of disabilities, facilitated by Dr. Pesach Gitelman⁴;
- Resource development as a requisite for social change, facilitated by Dr. Dvora Blum⁵.

On the day of the event about 150 people gathered to hear Naomi speak about "30 Years of Social Entrepreneurship", followed by a lecture entitled "The Changes that have occurred in the field of Developmental Disabilities in Israel and Beit Issie Shapiro's Central Role", given by Professor Arie Rimmerman⁶ from the School of Social Work, Faculty of Social Welfare and Health Sciences, University of Haifa.

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1. Maya Goldman, M.S.W., psychotherapist, counselor and lecturer in the area of families with children with disabilities. Founder of Kesher – Information, Counseling and Support Center for Parents.
 2. Batya Hodatov Beracha, M.S.W., Rehabilitation specialist and organizational consultant. Over the years Batya has worked developing services, programs and training; writing professionals materials; and facilitating, supervising, and lecturing. Batya worked for about ten years in Beit Issie Shapiro.
 3. Shimshon Keigrug Ph.D., is a member of the Beit Issie Shapiro Board of Directors and a senior lecturer in the Department of Social Work in the Ariel University Center of Samaria. Dr. Neikrug is a researcher in the areas of disabilities and ageing and has published in leading journals in Israel and abroad. In recent years he has partnered with staff at BIS to study the issue of quality of life of families with a child with disability.
 4. Pesach Gitelman Ph.D., Director of Project Development at Shekel – Community Services for People with Special Needs. Pesach was the first director of the Trump Institute for Continuing Education in Developmental Disabilities at Beit Issie Shapiro.
 5. Dvora Blum, Ph.D., Director of The Institute for Immigration & Social Integration at Ruppin Academic Center. In the past she has served as Deputy-Director of UJC-Israel. She is a member of Faculty of the Social Sciences at The Hebrew University of Jerusalem.
 6. See chapter 12.

Participants were then divided into the six discussion groups, each of which was allotted 75 minutes for the discussion. Each group was asked to focus upon the chosen issue in three stages:

1. To recall the way things were in Israel during the early years of Beit Issie's activity (beginning in 1981);
2. To look at the current situation and to note relevant changes that have taken place during the thirty years of Beit Issie's activity;
3. To discuss the ways in which Beit Issie Shapiro has contributed to bringing about these changes.

All the discussions were recorded and transcribed.

The current chapter will present a narrative of the activity of BIS that emerged from my analysis of the seminar transcripts. While the initial assumption of the analysis was that it would be based on the six issues identified prior to the event, after reviewing all the material it became clear that while each group indeed focused on the specified issue, many important themes seemed to cut across groups. I therefore chose to identify these emergent issues and to organize the material from all of the groups by way of these new categories.

In the rest of this chapter I will present a portrait of thirty years of extraordinary social entrepreneurial activity, as described by participants in the seminar (due to the constraints of space and context, only quotes related to the theoretical frame of the chapter could be included, thus much other valuable material from many of our partners unfortunately could not be included). Since an important part of the story is the people, those partners in mission who gathered together to celebrate Naomi's transition with her, it was important to us that the selected quotes from the seminar would be accompanied by descriptions of the speakers. We therefore asked all those whom we quoted to send us a self-description that best suits them for the purposes of the chapter. We have added these descriptions as footnotes.

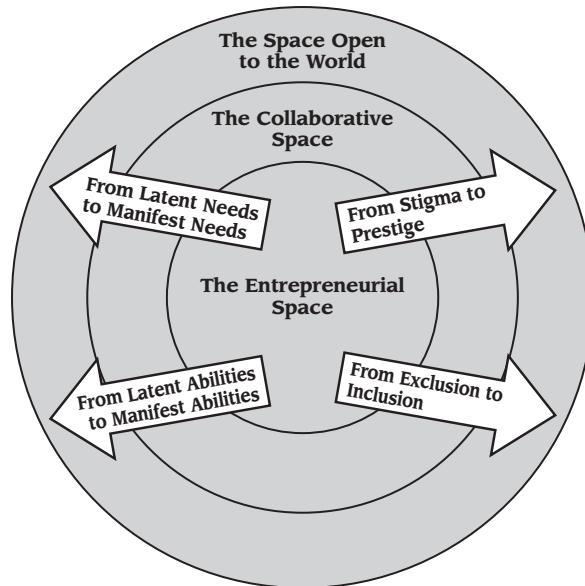
To frame this portrait I will briefly describe the conceptual framework that emerged from the analysis and that will serve to structure the presentation.

The Conceptual Framework: Beit Issie Shapiro's Action Strategy

How does a new enterprise engage an entrenched social reality and over time succeed in transforming it? More specifically, how does such an enterprise operate when the social reality that it wishes to change relates to the interface between the society and

an excluded population? The combined testimony of seminar participants provides first of all important insight into the original context in which Beit Issie began to operate - the details of which are often forgotten with the passage of time and change – and these recollections will set the entrepreneurial context. Moreover, they make it possible to trace the development of this interface between BIS and Israeli society as it relates to children with developmental disabilities and their families, and provide insight into the modes of operation BIS used in order to promote transformation over time.

Quotes from the seminar will be used to illustrate BIS's theory of action, as described visually in the following illustration:



Insert Figure 1: Beit Issie Shapiro's Action Strategies

The strategy can be divided into two dimensions: 1) *the social spaces in which activities take place*, and 2) *vectors of change over time* in these social spaces.

The three social spaces

The three social spaces that emerged from the analysis are: The entrepreneurial space, the collaborative space, and the space open to the world. The following are descriptions of each of these spaces and of the activity that takes place in each:

1. The Entrepreneurial Space: The space of an organization whose members are

encouraged and enabled to innovate in providing solutions to the needs of clients.

2. The Collaborative Space: The interface between the organization and its functional environment, which is perceived as a field of opportunities for collaboration in advancing shared goals of change.
3. The Space Open to the World: In BIS's action strategy there are essentially no pre-set boundaries. What begins locally can become national and global. Opportunities may arise anywhere, and the organization can develop in unexpected directions.

The four vectors of change over time

Transformation is multidimensional and requires movement in multiple and mutually reinforcing directions. Beit Issie Shapiro consistently and simultaneously targeted its energies and resources to proceed along the following four vectors of change, both within the organization and in its relations with its environment. All of the vectors represent directions of change over time in the ways in which society related to children and adults with disabilities and their families, and in the ways in which these same people related to themselves and their place in society.

1. From exclusion to inclusion: Moving from a situation in which the lives of people with disabilities are nearly entirely separate from the rest of the society, to one in which they are fully and naturally integrated;
2. From stigma to prestige: Movement from a situation dominated by negative and irrational perceptions of people with disabilities, to one in which it becomes normative and even fashionable to become involved with them.
3. From latent needs to manifest needs: Movement from a situation in which society is blind to the human needs of people with disabilities and their families, to a situation in which these needs are seen, solutions exist, and the rights to treatment, accessibility and accommodation are honored.
4. From latent abilities to manifest abilities: Movement from a situation in which people with disabilities are related to exclusively as people who need help, to one in which they are seen as people with abilities that can and should be developed for their own and society's benefit.

Descriptions of the Entrepreneurial Context

In the following section I will quote from the words of seminar participants who related to the first task posed to them: To remember the situation in Israel in the early years of Beit Issie Shapiro's activity (beginning in 1981). These memories provide a glimpse of the realities relevant to people with developmental disabilities in Israel at this time, and provide perspective regarding changes that have taken place in this field in subsequent years.

In its early years Beit Issie Shapiro's vision and modes of operation were dissonant with those of most existing services. In the words of Dr. Avi Ramot⁷:

Naomi told us what she wanted to do, develop real community services for people with developmental disabilities. She presented us with a picture of a vision. What we see today is actually very close to the vision she painted in 1980, but at the time it sounded delusional.... After five minutes with her and her incredible staff you couldn't grasp how you could one day be sitting there with them and on the next day you would be sitting in the Ministry. It was like living in two different worlds.

Helene De Lowe⁸ recalled the circumstances that led to her family to initiate early childhood services for children with special needs in Israel:

We lived in California and wanted to make Aliyah, but we needed to find a therapeutic day care center for our third child, Aaron (of blessed memory) who was born with severe physical and mental challenges.

On a pilot trip in January 1979, we visited many facilities in Israel, but found none that were suitable for Aaron's disabilities. It was clear to us that we might have to develop such a facility ourselves. Sadly, Aaron died 2 months before we made Aliyah in May 1979. We received donations in his memory to start something for children with problems similar to Aaron. We did a survey from Haifa to Beer-Sheva to help us evaluate what the needs for high risk babies would be. Our conclusion was that there were very limited

7. Avi Ramot, Ph.D., Director of Israel Center for Accessibility at Shekel; Former Director of Community Services for People with Mental Retardation; Former Director of Services for People with Special Needs at JDC-Israel.
8. Helene (Chaya) De Lowe, Special Education, San Diego State University (California). Founding Director of the Aaron De Lowe Early Intervention Center for Young Developmentally Delayed Children at Beit Issie Shapiro and a pioneer of Early Intervention in Israel (1981). Mother of 3 and grandmother to 6 (all in Israel).

services available. This led us to open the first program of the Aaron De Lowe Early Intervention Center in 1981, an Infant Stimulation program for at risk infants – up to 2 years of age which focused on both the child and his family.

Dr. Lea Shaked⁹ recalled the approaches toward children with developmental disabilities and their families that had been commonplace in Israeli society during its early years:

It's not that in the first years of the state children with intellectual disabilities were all in institutions.... In fact, many of these children were living in monasteries.... In Jerusalem the Jewish children with intellectual disabilities whose parents could not care for them lived in convents in the care of the nuns. Till today there are such children whom the nuns cared for and educated. Really it was only much later that anyone thought of the whole issue of caring in the community for children with intellectual disabilities.

At the time the State of Israel did not know how to tell parents that their children were autistic. Many times they came into the room and said 'you have an autistic child, bye'. And the parents were left in total shock.... The first place to identify the need to accompany parents was really Beit Issie Shapiro.

In retrospect, however, it can be seen that additional processes were under way that supported the directions that BIS promoted. For example, while the primary societal response to children and adults with intellectual disabilities in Israel had been institutionalization, during BIS's early years there were already early signs of change.

Dr. Gilada Avissar¹⁰ notes some of the changes that took place during these years:

The institutions took children from an early age, and they stayed there until adulthood... with little if anything to do. There were educational settings in the institutions, but these were unrelated to the Ministry of Education. It was only in the early 1980's when Shimon Sachs became a national supervisor that he began to open schools supervised by the Ministry of Education.....

Somewhere during the second half of the 1980's we began to experiment

9. Lea Shaked, Ph.D., Former National Supervisor of Special Education Services in the Ministry of Education, currently a lecturer in the Department of Teacher Training in Achva Academic Campus.
10. Gilada Avissar, Ph.D., Senior lecturer and researcher in the areas of curriculum for SEN students and inclusion at Beit Berl College. "I have been affiliated with Beit Issie Shapiro from the start and was involved in different educational projects, the last of which is research of the ten-year partnership between Beit Issie and Beit Berl".

with 'inclusion'. An institution for infants in Kfar Chasidim in the north closed down and the owners said, 'wait, we are on Hagefen Street, why shouldn't the children go to the school one street over?' This was extremely controversial at the time, but they chose the children. This was the first time that young children who lived in an institution run by the Welfare Ministry went to school in the city.... It was an astonishing innovation at the time.

Dr. Trevor Segal¹¹, spoke of the state of dental care for children and adults with developmental disabilities when he began:

I am a dentist. A friend of mine, named Dr. Brian Braude¹² , and I were talking one day, I don't know how many years ago, that we had a patient with disabilities and there was no service available for him. There was something in Hadassa in Jerusalem, there was a long waiting list and there was no follow-up care. And to make matters worse it was very expensive, so dental care was very low on parents' list of priorities. And back then for private care you had to order an anesthesiologist. He would come with his bag and move the patient to a different room. Most of the dentists weren't willing to accept these patients, and if they were willing they didn't know what to do, not that I knew. And then we talked and we said 'let's try to do something on a volunteer basis, to find a place'. That was the first step.

Dr. Avi Ramot¹³ noted the changing of the guard that was taking place in the Ministry of Welfare at the same time that BIS was getting off the ground, with young professionals in key positions who could recognize the potential value of the new phenomenon:

Just around that time a new generation of professionals was taking its place in the Service for the Retarded, including Dr. Meir Hovav at the head. You have to understand that when I was appointed Director of Community Services for People with Mental Retardation in Israel, some of the regional supervisors were older than my own parents.... When my boss Meir Hovav said that a certain De Lowe family was looking for a way to make good use of \$40,000, and we didn't know what to do with it, we were very glad to hear that they linked up with Naomi Stuchiner, because then we knew that the money would be well used, as indeed it was¹⁴.

11. Trevor Segal, M.D., was one of the founders of the Naomi & Shimon Dental Clinic at Beit Issie Shapiro.

12. Brian Braude, M.D., graduated in Dentistry from the University of Wittwatersrand in South Africa in the early 1970's, and was one of the founders of the Naomi & Shimon Dental Clinic at Beit Issie Shapiro.

13. See note 7.

14. The connection between BIS and the De Lowe family was indeed made, and one year after BIS opened, the Aaron De Lowe Early Childhood Center was opened within it.

Yoav Kraiem¹⁵, a disability activist who was a child during the early years of BIS, reminded his group that even while most children with mental retardation were put in institutions, despite his developmental disability he and some other children grew up at home and received quality services in the community:

I can tell you that I did receive most of the services we'll be talking about, even then, I was in a special pre-school run by Ilan that provided all the treatments, just like what happens today in the BIS pre-school. I got occupational therapy, speech therapy, physical therapy, and even hydrotherapy... And later the Ilan afternoon program Spivak in Ramat Gan took in children from the whole area. What is different now, I think, is that today there are more services of this kind at more places in Israel, but the essence of the services already existed.

Zvi Kenig¹⁶ disagreed with the above assessment, stating that in his opinion Israeli society had undergone a much more significant change during this thirty-year period than Yoav Kraiem had indicated:

There is no comparison between what existed thirty years ago and what exists today. For instance, the whole issue of awareness, even the parents perceive themselves and their children differently from the way they used to. Nowadays the government, with new laws and services, relates differently to people with developmental disabilities and their families. Attitudes in the community have changed, people are accepted and integrated today when once they were pushed aside.

To summarize the description of the entrepreneurial context: BIS came into being in a reality in which the dominant approaches towards children and adults with developmental disabilities and their families were exclusionary and stigmatic. BIS indeed introduced a new outlook into the field, with ideas, attitudes and professional approaches that were in sharp contrast to and even in conflict with the prevalent paradigms. At the same time, BIS was not alone in the field – there were already other organizations that provided quality services in the community for children with disabilities, and around the same time a new group of functionaries, young professionals who were open to new approaches, were taking their places in the Ministry of Welfare. There is no doubt that the existence of such allies contributed significantly to the success of BIS in bringing about change in this field.

15. Yoav Kraiem, a leading disability activist in Israel, was spokesman for the Israeli Human Rights Organization for People with Disabilities during the 1991 and 2001 mass protests. He was a candidate on the Meretz Party list during elections for the 16th Knesset.

16. Zvi Kenig, Former Deputy Mayor, Education and Welfare, Municipality of Raanana.

The Partners Speak about the Three Spaces

The next section of the chapter will bring quotes from the seminar that point to BIS's activity in each of the three spaces detailed above: The entrepreneurial space, the collaborative space, and the space open to the world.

The Entrepreneurial Space

The first component in the Beit Issie action strategy was to create and sustain an organizational space in which members are encouraged and enabled to innovate in providing solutions to the needs of clients. Many seminar participants noted that from the beginning BIS - with Naomi Stuchiner at its helm - generated unforeseen possibilities for talented professionals to innovate for the benefit of children with developmental disabilities and their families. In this section we will relate to the aspects of this organizational culture that created an "entrepreneurial space".

Lili Levinton¹⁷ recalled her first encounter with Naomi, and how quickly it turned into a job interview:

My first encounter with BIS was in 1986. I was working at the time with families who had a child with special needs, and as part of my psychological-community orientation I helped parents look for frameworks for their children. In this context I came to BIS and met with Naomi in order to interview her about the service and see if it was suitable for a client. I can't help but laugh every time I recall the story. No more than two minutes passed before Naomi began to interview me. She soon picked up the phone and called Chaya who was directing the Raanana center (BIS was still in Herzliya) and said "I really want you to meet this girl"...

Naomi Pugatsch¹⁸ described Beit Issie's rapid and extraordinary response to her own daughter's needs:

I had been volunteering in my free time at Beit Issie when I was a mother to two adorable and healthy children. This was when I still naively thought that their services are "for other people" and it could never happen to me. Within a few months after Tamar, my third child was born, we realized that she had developmental problems. At the time Beit Issie did not have a program for such small babies. But they came to the rescue in the best way! They prepared

17. Lili Levinton, M.A. Developmental Psychology, Director of the therapeutic daycare services at Beit Issie Shapiro.

18. Naomi Pugatsch, mother of Tamar, former student at Beit Issie Shapiro.

a stimulation program just for Tamar, and came to visit us once a week at our home from the time she was a few months old, until her first birthday. At the age of a year, in 1983, Beit Issie received a grant from a Swiss organization to open a new early intervention program, and initiated a pilot study to see how valuable early stimulation is for children that are just one year of age.

Elvira Gruner¹⁹ spoke about Naomi Stuchiner's surprising openness to ideas that she raised, and her willingness to take risks in order to provide services that made a difference for the children and their families:

When I first met Naomi one of the things that impressed me most was that I had lots of ideas and Naomi liked them all, and I found this so strange. For example, I remember that one of the problems was that there was nothing for the children to do in the summer, and I came to her with an idea of doing camps. I was the one who initiated the camps on the beach.... Each time I took the children to the beach in the bus, Naomi would pray that I would come back safely with all of the children. It was a world of initiatives, not rules. We didn't know about rules. Naomi said "it's okay, Elvira, do it." And following Naomi I did it.

Batya Hodatov Beracha²⁰ related to BIS's striving to identify needs that were not being met, and precisely there to develop new services:

Wherever there was a need, that's where we went. That's how it was with most the services that Beit Issie developed: pre-school, school, respite care program, afternoon program..... For example, there were no respite care facilities at the time, ours was among the first and only ones in Israel that gave support to families, and it was all the result of pursuing the goal of helping families with their real needs. Wherever something was lacking that's where we moved in and started developing.

Tuvia Stuchiner²¹ related to what he considered the most critical component of Naomi's mode of action – identifying opportunities and taking advantage of them – that enabled BIS to develop continually over the years:

19. Elvira Gruner, is a clinical and educational psychologist in special education from Argentina who set up the first therapeutic playroom in BIS. She is a graduate of Wingate, studied movement therapy, painting and sculpture, and has a degree in alternative medicine. She is currently a lecturer in the Reidman College and has a private practice.

20. See note 2.

21. Tuvia Stuchiner is a hydrotherapist who established BIS's Hydrotherapy Center in 1991. He developed and led hydrotherapy training in BIS, leading it to become the largest hydrotherapy training center in the world. He is among the founders of the Israeli Hydrotherapy Organization. Tuvia continues to teach in Israel and abroad.

Naomi did not set a goal, she established the values and set a direction and a way of moving ahead. If she had just set a goal, we would have reached that goal and then more or less stopped. She set values and direction. We all live with opportunities that we let pass us by. We don't always know how to make the most of them. Naomi knew how to recognize opportunities. If this suited our direction, she could see the advantage of turning it into something practical. It used to make me crazy. After her conversation with Helene De Lowe she came home and told me: "I just met this amazing couple! They have exactly what we need in order to gain entry into the field of early childhood and we're going to do it." She never wasted time when it came to taking advantage of an opportunity.

Dr. Udi Yoge²² spoke of Naomi's vision that enabled her to adopt others' ideas in order to promote BIS's social agenda:

Despite the fact that Beit Issie was an educational/therapeutic institution and not a medical facility, Naomi enabled us to set up a medical service. She had the vision to understand that if it wouldn't be set up in BIS, it probably would not be a community-based service. It would only be set up within some kind of hospital setting. And that is the greatness of a person who can see ahead... At the time everything was based on the volunteer work of wonderful people, who initiated and set up the service, reached out in many directions and found funding...

Nira Stern²³ related to Naomi's ability to think "out of the box", to the effect of this ability on BIS's organizational culture, and to the backing that she experienced in the organization that enabled her to move forward in her specific area:

Out of the box thinking begins with listening to new ideas and making room for them. That can't be taken for granted, because earlier I had wanted many things, but very rarely did someone say "okay, you have an idea. Is it good? Okay let's give you backing." And there was systemic thinking about these ideas, not only Naomi's thinking out of the box, but enabling people to think together, to develop a conversation around the idea, with a great deal of emphasis on inter and multi-disciplinary thinking at all times. There was discourse among different professionals, and it was inspiring, and it inspired us to go beyond the existing models. The moment you have backing and you see that someone believes that your idea can happen, it gives the people working on the idea the strength to keep moving ahead.

22. Udi Yoge, D.M.D., Director of The Naomi & Shimon Dental Clinic at Beit Issie Shapiro.

23. Nira Stern, B.Ed., M.P.A., is the Director of The Jonah Press Sport and Recreation Center at Beit Issie Shapiro.

Finally Angela Harding²⁴, a BIS partner in London who participated in the seminar, described an element of the BIS culture that encouraged the growth and development of everyone who becomes engaged in the organization's mission:

I think that one of the most important things about Beit Issie is that it has created a culture of questioning and self-discovery. Naomi is always pushing the boundaries, and that is a very rich way to get everybody growing.

To summarize, an organizational space was created in BIS that was characterized by a total commitment to promoting the quality of life of children with developmental disabilities and their families, by an exceptional openness to ideas, and by an organizational flexibility that enabled the organization to identify and make the most of opportunities that others would have missed. Staff in BIS experienced extraordinary opportunities to develop their ideas and to develop as professionals and as human beings, in the context of multi-disciplinary discourse that focused on developing holistic solutions while backing the fulfillment of professional dreams.

The Collaborative Space

From its inception BIS was oriented to much more than providing a quality service, it was driven by a vision for changing society. By definition this required working with others, others who did not experience themselves as sharing the same perceptions or interests. Drawing upon her background as a community social worker, Naomi perceived her functional environment as a field of opportunities for collaboration in advancing shared goals of change. She worked consistently and proactively with stakeholders in the BIS organizational environment, harnessing their positive and collaborative energies, and building their commitment towards shared goals of change.

The following quotes reflect how this mode of action has been experienced by those inside and outside of BIS:

Dr. Baruch Ovadia²⁵ spoke of Naomi's extraordinary ability to mobilize partners and to motivate them to work together in order to advance a shared and important interest:

The moment she brings together a number of people from the community, and the people understand that what they are doing contributes to them and their surroundings, there is no need for public relations. They are partners, they are involved, they are engaged out of a personal interest. This is what

24. Angela Harding, founder of The Speech, Language and Hearing Centre at Christopher Place, London.

25. Baruch Ovadia, Ph.D., formerly in charge of Social Work services in 'Kupat Holim Clalit' (General Sick Fund) 1976-1993, where he first got to know Naomi.

she does and it is what she taught the students she supervised. It's what they learned: To bring together people with a common interest in the community around a matter of great importance.

Advah Naveh²⁶ described the special relationship that developed between BIS and the Raanana Municipality, a relationship that broke the existing norms:

Ra'anana was in my supervisory jurisdiction when I worked as a supervisor in the Ministry of Welfare. Naomi brought about a transformation in the way that local government related to Beit Issie Shapiro. No longer was it another institution for the "retarded" located on the margins of the community, rather it was an institution in which Raanana took pride. Naomi mobilized the entire Raanana community in a relationship that was always mutual. People volunteered and contributed but also felt that they benefited and they were proud to be associated with the Beit Issie community. The name of Beit Issie Shapiro was heard everywhere. Whenever and wherever there was an event Naomi was there, emphasizing through her presence and voice Beit Issie's special status in the community. In this way she strengthened the community's and the municipality's involvement and commitment.

Miriam Cohen²⁷ described Naomi's special investment in cultivating the relationship with Ra'anana's mayor at the time, Zeev Bielski²⁸:

In my opinion another thing that should be learned from Naomi is how to cultivate relationships with mayors, because the Ra'anana mayor and Naomi went hand in hand, and that was critical. It is true that Zeev Bielski's character was a good match for Beit Issie Shapiro, but Naomi and her staff nonetheless worked hard to cultivate their partnership with him.

Shlomit de-Vries²⁹ spoke of BIS's exceptional ability to leverage collaborations:

As a foundation that during its 15 years has supported the activities of over 2000 organizations... we have found that sometimes in one city or town there

- 26. Advah Naveh, M.A. in Psychology and Social Work, certified family therapist, Welfare officer for the enforcement of the 'Service for the Mentally Retarded Law' at the Ministry of Social Affairs and Social Services. Served as a supervisor in the Division of Services for Persons with Developmental Disabilities (then The Service for the Mentally Retarded) for about 20 years until her retirement, including supervision of Beit Issie Shapiro.
- 27. Miriam Cohen, M.A. in Community Social Work, Planning, and Social Administration, specialized in Developmental Rehabilitation. Past director of the Service for People with Mental Retardation and their Families in the Community at the Ministry of Welfare.
- 28. Former Mayor of Ra'anana, 1989-2005.
- 29. Shlomit de-Vries, CEO of the Ted Arison Family Foundation.

are four organizations, each of which does amazing work, but just try to bring them to sit together and pool resources... Everyone likes to use the word "leveraging." With Beit Issie it just happened so naturally and smoothly.

Dr. Dalia Nissim³⁰ shared first hand her experience as a professional working in the system for years in areas connected to the activity of BIS:

I have been accompanying Beit Issie Shapiro almost since it began... There's something special about the way they create that feeling that you are committed because you want to be committed, because together perhaps we might be able to create something new, and it feels good to be a part of something big and important, which I think this is.

Dr. Nomi Werbeloff³¹ described her experience in creating partnerships in the community when she led the Accessible Park project:

I came to BIS as a third year student in community work and stayed until I was about to finish my doctorate..... My last project, my "baby," was the accessible park, which was a very special experience for me in creating partnerships in the community. We sat with the parents and mapped their needs and we sat with pre-school teachers and other educational frameworks to understand how they would be able to use the park afterwards. We discussed how we could pool resources and make the most of the strengths and advantages of everyone in order to produce something that would go far beyond the initial investment in the physical infrastructure of the park, creating something that would really be a meeting place for the community that would be full of activity. It was a wonderful experience to work in partnership with so many local and national organizations. I learned how to really build something, and how afterwards to make it take root in one place and pass it on to others.

Shosh Kaminsky³² spoke of the great pleasure she derives from working in the context of collaborative relationships that have been developed over the years:

I think one of the most pleasurable things in my job is the partnerships that are inherent in all that we do, it is simply pure pleasure to work with many people

- 30. Dalia Nissim, Ph.D., is currently Director of Knowledge Development, Knowledge Management and Training in the Department for Treatment of People with Mental Retardation at the Ministry of Social Affairs and Social Services. She has been connected professionally and personally with Beit Issie Shapiro for 25 years.
- 31. Nomi Werbeloff, Ph.D., researcher and lecturer, Bar Ilan University and Ashkelon Academic College.
- 32. Shosh Kaminsky, M.S.W., Director of Family & Community Development Department at Beit Issie Shapiro.

and many organizations, including government ministries..... It feels great to have so many partners and to come to work and to do things together; to feel that you are not alone in dealing with the challenges, to experience collegiality in relations with a range of organizations and with parents. I think it is these feelings that have kept me in the same place of work for so many years.

To summarize this section, the statements quoted – some from people who work (or worked) in BIS, and others from people who experienced the organization as partners in different ventures – point to the special collaborative relations that are woven between people working within the entrepreneurial space (BIS the organization) and others who work in its functional environment. Relations in this collaborative space are closely tied to BIS's mission as a leader of social change. It is in this space that a shared sense of meaning and fulfillment derived from the opportunity to take part with others in highly valued and highly successful activity is turned into extraordinary leverage for generating change and development.

The Space Open to the World

This next section will bring quotes from seminar participants that demonstrate BIS's openness to social spaces beyond its direct functional environment. This openness can at times be observed in the organization's responsiveness to opportunities that present themselves, and at other times entry into far-away fields is proactively initiated in search of solutions for the organization's professional or resource development challenges.

Miriam Frankel³³ spoke of how the uniquely successful work being done in BIS attracted many parents from areas far from Ra'anana, who came in the hope of receiving high quality services for their children:

I think that one of the most exceptional things, and here I put on the hat of "mother of" is that at some stage, people from Jerusalem, Tel Aviv and many other places throughout Israel were made aware of the professional level of Beit Issie. And they made decisions to move to Ra'anana to receive the services they needed to keep them together as a family. That is to say, that at some stage the success created a momentum that affected individual families and the development of Beit Issie at the same time.

33. Miriam Frankel, past volunteer coordinator at Beit Issie Shapiro, Deputy Director for Resource Development, Reuth.

Daniel Sror³⁴ spoke of how BIS's success was based on the one hand on recognition of the organization's limitations, and on the other hand on a deliberate strategy to make the most of its advantages in order to create broad impact:

What I remember, one of the first things I learned when I became more seriously involved in BIS activity, was that we cannot care for all the children. But we can create a superb model that others can learn from, copy, and implement in many other places. And if we create a model that others will want to copy or to imitate the results will ultimately be much better than if we tried to do it all ourselves. And if we look now from the perspective of years, it worked.

Chemda Zuckerman³⁵ related to the dissemination of innovations first developed in BIS in legislation, and in the professional standards and budgets of the Ministry of Welfare:

Thirty years ago when I worked in Beit Issie we did the first mainstreaming program in Israel. Today there's a law and there are entire programs that are supported by the state. But it needs to be said that many of the programs and services developed in Beit Issie Shapiro for families became services provided and funded by the government. This includes models for working with the extended family, and the creation of a system that wraps around the family.... Today the services do things that once were considered innovative, as part of their worldview and daily professional practice. And you really have to attribute this to its source. It all really began in Beit Issie Shapiro.

Dr. Udi Yoge³⁶ described the impact of the BIS dental clinic upon dental care for children and adults with developmental disabilities throughout the country:

I see the influence of our little clinic on this field on the national level. We have led a number of revolutions in terms of the types of treatments and the style and nature of treatments. We had to overcome many obstacles from the government ministries, the Ministry of Health and the Ministry of Welfare... Undoubtedly there are broad and long term impacts, and I think the situation today with regard to dental treatment of people with special needs is radically

34. Daniel Sror, Adv. is father of Yuval who was a student at BIS for 8 years, and a member of the BIS Board of Directors for over 10 years. He is a partner in law firm specializing in representing victims of medical malpractice.

35. Chemda Zuckerman is a social worker specializing in rehabilitation. During the years 1987-1998 served as Director of Community Services at BIS. Currently serves as a rehabilitation supervisor in the Rehabilitation Department of the Ministry of Social Affairs and Social Services.

36. See note 22.

different from what it was when we began. This isn't something that happens in a day, it's a slow process, and I think that today the clinic is already looking in other directions because there are enough, not enough, but more and more places and services that are providing treatment to this population, whereas in the beginning there was a void. And that is one of the outcomes of this long process.

Rivka Shai³⁷ noted that in addition to the direct impact on Israeli society that BIS made over its thirty years, a second level of impact has now become apparent: BIS was a training ground for much of the current generation of leadership in the field of developmental disabilities in Israel:

Beit Issie Shapiro has made an enormous contribution to this field. Many of our partners in the government worked in the past in Beit Issie and developed there professionally. If we look around now we can see that many of the people doing excellent work and collaborating across organizational boundaries are products of the Beit Issie "school."

Amy Slater-Ovadia³⁸ described the powerful presence of BIS in the United States as well:

There are thousands of children today in the United States who ride bicycles for the children of Beit Issie Shapiro... They talk about their friends, they talk about the State of Israel...And it's really very important abroad, to be in touch with the beautiful side of Israel. It's not about what's in the news, but rather about children and families and it's incredible.

In summary, BIS constantly ventured outward in many and varied directions. BIS ventured out of Raanana and impacted upon the quality of services throughout Israel; it ventured out of the third sector, formed partnerships with businesses and philanthropists, and impacted upon legislation and upon the standards, manpower, and budgets of government ministries; it ventured out of the boundaries of the State of Israel and connected to donors, professional communities and Jewish communities throughout the world.

37. Rivka Shai, Director of the Department for Children and Youth with Disabilities at Joint – Ashalim.

38. Amy Slater-Ovadia has been connected to BIS since 1998 when she was the first Coordinator of Volunteers for Resource Development in Israel. She later became Director of Resource Development on the West Coast of the United States, and National Director of the Milestones Program in the United States.

The Partners Speak about the Four Vectors of Change over Time

The following section will bring quotes from the seminar that relate to the four vectors of change over time that characterized BIS's activity: From exclusion to inclusion, from stigma to prestige, from latent needs to manifest needs, and from latent abilities to manifest abilities.

From Exclusion to Inclusion

Perhaps the most obvious vector of change that BIS promoted is reflected in the move from exclusion, or even expulsion, to inclusion in the community. When BIS began, people with developmental disabilities were largely invisible to the general public, as they, and institutions that society provided for them, were put in nonresidential locations that greatly minimized the possibility of contact. The decision to insist, against the objections of community members, on placing BIS in the heart of a residential neighborhood, took this issue head on by creating "facts on the ground" that changed the predominant spatial reality. The actions and considerations related to this vector are reflected in the following quotes from former BIS workers who tell the story of how BIS negotiated this change:

Chemda Zuckerman³⁹ described the professional worldview behind the insistence – exceptional at the time – to establish BIS in a residential neighborhood:

Now we don't even notice that frameworks for children with special needs are in the middle of the community; it seems trivial. But thirty years ago to set up something in the heart of the community was very exceptional. I remember that we had a professional worldview that we should be in the heart of a residential neighborhood, so that the families who come with their children will feel that their child is accepted in the community. And I remember that we went from family to family in the neighborhood around Beit Issie Shapiro, to tell them about children with special needs, what it's all about.... At the time we actually thought about how the families would park their cars in a residential neighborhood, would come into a place not in an industrial area.... You can't change attitudes by talking about it. You have to do it. And here was an experience that the parent took his child, stopped in the heart of a residential neighborhood, went into a beautiful building – where great attention was paid to the small details, regardless of the money – precisely to meet that need of the parent, that he should have a pleasant experience when

39. See note 35.

he walks into the building with his child.

Lynn Lochoff⁴⁰ recalled her work as a community worker in BIS during these years, and the strategies that ultimately made success possible:

They were just moving from Herzliya to Ra'anana and when people in the neighborhood heard that an institute for the "retarded," and the "severely retarded" no less, was being built, complaints were filed in the municipality. Petitions in protest were even circulated... Naomi gave me the job of going from house to house to try to change their minds. I spoke with the neighbors individually rather than in a group, and I was able to talk with them about their fears and concerns, how would it bother them that Beit Issie would be there. In the beginning I heard 'maybe they will be violent, maybe they will be contagious'. We worked step by step with the community. This was exemplary community work: How to transmit the message to residents that they would benefit from a facility they feared. We convinced them that we were open to any request, that they could come to us and use our facilities. Slowly but surely we began to contribute to the community, going into the school and giving lectures, sending a representative to every community event. Over time they felt that we were doing them a favor when came into our building and to feel pride at what they saw. In the end community representatives stood on the Beit Issie board and I think that one of us was on the community council.

Batya Hodatov Beracha⁴¹ shared her perspective as someone who grew up in the new reality fostered by this change:

I am from the younger generation, and it is inconceivable that thirty years ago there were no services in the community – no early childhood frameworks, no special school, and no special education – to say nothing of a policy of integration in regular schools.

In summary, in order to change the entrenched social reality in which many children and adults were expelled from the public space to institutions located in isolated areas - in which they were "far from the eye and far from the heart" - it was necessary to establish an anchor in the community for the new worldview. This turning-point was created thanks to the insistent and sensitive professional action at the time that BIS was being established in the heart of a residential neighborhood in Raanana. This accomplishment later formed the basis for the activity of many others who identified with the direction of the change and who acted too to create a different social reality into which the next generation was born.

40. Lynn Lochoff, Managing Director at Beth Protea.

41. See note 2.

From Stigma to Prestige

At the time that BIS was established, stigma with regard to people with developmental disabilities was deeply rooted. During the seminar Shosh Kaminsky⁴² recalled a powerful experience she had had a number of years before she began to work at BIS:

Around twenty years ago I had two neighbors who worked in Beit Levzeller and one of the things they used to do was to go for a walk with a number of residents, and they used to bring them home to us. And one of these times they went up the stairs with a group of residents just at the moment I was going down the stairs with my son. They went by, and my neighbor opened her door and said in a very distraught voice: 'Shosh, you have to talk to them that they shouldn't bring these people to our house.' I looked at her and said 'why shouldn't they come, I don't understand, how does it bother you?' She said to me 'you see that your boy is little and what it is doing to him?' And I carried that scene in my mind for years. I am a social worker by profession so I know all about stigma, but the feeling of actually seeing it in a person, was terribly powerful and extreme.

BIS brought into this reality a radically different view of children with developmental disabilities and their families. Sharon Bacher⁴³ described how when she began writing materials for fundraisers for the organization she needed to make an essential shift in the language she used: from language designed to arouse pity, to language designed to change perceptions and attitudes:

I came into the field of writing after I had worked for several years as a social worker. I found that a whole new vocabulary was being used. I learned not to use words like "charity," nor to think of children as getting pity and needing charity. Instead I learned to think of resource development as raising money for children to get the education that they deserved; that was their right. And that led to a fundamental shift in attitude... We were doing things that were not necessarily profitable but Naomi felt that the issue of changing attitudes was extremely important, and that's what was happening.

Dalia Nissim⁴⁴ related to BIS's professional activity and aesthetics, and to the messages they transmitted:

42. See note 32.

43. Sharon Bacher, M.S.W., formerly Manager of the International Resource Development Department at BIS.

44. See note 30.

Beit Issie had a worldview of how to act to change people's attitudes. It meant taking action by bringing people into the organization as well as going out into the community. It was a very active stance to show and convey the egalitarian relationships. On the other hand there were things that they didn't do overtly but gave a lot of thought to, such as the aesthetics of service provision, real aesthetics. That is, there will not be an installation or a wall or a stone that will not be so aesthetic and fine as to convey to all who enter the building that people with such difficult needs, people with mental retardation and other difficult disabilities are entitled to high standards.

Arie Shemesh⁴⁵ spoke of the respect that BIS brought to the field of developmental disabilities:

I think that what Beit Issie did more than anything else was to bring a lot of respect to the field, and that's why it was able to get things moving. When I came there I saw Naomi and I saw the prestige she brought to the issue.... People were jealous and wanted to be like that. That didn't exist before Beit Issue. This story of giving respect to people, to families, is the key to moving forward. It's worth being a partner to such an enterprise.

Amy Slater-Ovadia⁴⁶ testified that this component of excellence and high aesthetic and organizational standards is unique to BIS even from an international perspective:

I worked with the community in the US, Jews who didn't know anything at all about this field in Israel.... I worked in fundraising in many places in the US, and I saw many wonderful organizations for special needs. There is no place like BIS in the United States; not the collaboration nor the vision. And at BIS events are always tip-top. If it's a bar mitzvah, it's done with the same love and care for detail as you would do for your own child.

In summary, for BIS it was not enough to provide quality therapeutic services to children and their families. An essential feature of the organization was the respect and dignity that it communicated, both to members of the population and to the surrounding society. This respect was reflected in the aesthetics of every detail, in the high standards and in the striving for innovation and excellence. In this way BIS, which had tied its destiny to that of children with developmental disabilities and their families, brought prestige both to itself and to the populations that it served.

45. Arie Shemesh, National Supervisor of Adoption Services in the Department for Treatment of People with Mental Retardation in the Ministry of Social Affairs and Social Services.

46. See note 38.

From Latent to Manifest Needs

An important aspect of the BIS strategy was to awaken latent needs by providing services. Beit Issie Shapiro develops services, and once people know that it's possible to do something about the need, it arouses both awareness and appetite. In other words, when people understand that they have a right and that someone can provide them with what they need, they say: 'why should someone else get this and not me'. That creates a demand that comes from the field, from the parents, to expand and improve the existing services and entitlements.

Some of the innovative services first developed in BIS with an eye to meeting previously unmet needs of children with severe developmental disabilities - such as the Sneuzelen and hydrotherapy, were initially regarded with skepticism by mainstream services. Riva Muskal⁴⁷ noted for example that

Beit Issie Shapiro has made a major contribution to innovative breakthroughs that promote an improved quality of living for people with intellectual disabilities and their family members. For example, when Beit Issie first began to promote the development and use of hydrotherapy it was perceived as a luxury. It is now recognized as an essential and recognized therapeutic modality that makes a significant and important contribution to people with special needs.

Susie Schreiber⁴⁸, proud mother of Ori who also participated in the seminar, highlighted the fact that the successful early treatment that Ori received enabled him to be educated in the regular school system, but his continued development required that the school system change its approach to the needs of children with disabilities:

Our son Ori got excellent care in the special education framework of Beit Issie Shapiro and Spivak, but when we decided to integrate him into a regular school we discovered that because he had left the special education system, he was no longer entitled to the special paramedical treatments that he so desperately needed. This created a tremendous financial and practical burden for us, and what was perhaps most difficult was that there was no one in the entire educational system to whom we could turn; we were left entirely on our own. Naomi took it upon herself to create a solution, and that's how it all began. I really think it began with us.

47. Riva Muskal, Executive Director, The "Shalem" Foundation for the development of services for people with intellectual disabilities in the local councils.

48. Susie Schreiber, proud mother of Ori, a former student at Beit Issie Shapiro.

Chemda Zuckerman⁴⁹ related to the critical role that providing services to the children played in freeing up space for discovering the needs of the parents and other family members:

I think we found that often parents of children with special needs don't have the space they need to care for themselves, because they need always to take care of their children. The way I understand it, the development of services for the children freed the parents from that place and created the space where they could pay attention to their own needs and feelings. Because before there were services for the children – camps for the kids, after-school programs – the exhausting, burdensome, day in and day out care for the children left them overwhelmed. I think that development of the services that provided solutions for the children also made it possible for us to intervene in the families and give the families space for themselves. We saw the broader family, not just the parents. The siblings of the children with disabilities, the grandparents, the surrounding community. I think that the first grandparent group in Israel was in Beit Issie, and the same goes for sibling groups.

Dafna Kleinman⁵⁰ spoke of the transition from latent to manifest dental needs of people with developmental disabilities living in the community:

Two days ago I attended a Knesset committee meeting that dealt with public complaints. Also in attendance were representatives of two organizations, one for adults with CP and another that represents a broad range of disabilities. They came to complain about the fact that, as opposed to those living in institutions, they did not have access to dental care. They came to say 'we represent a very large group of people with disabilities who live in the community, who live just on the social security stipend, and it is hard for us to care for our teeth, because we have special problems. We ask the Knesset to pass a law or a regulation so that the Ministry of Welfare or the Ministry of Health will care for us'. And I think that is the significant change that has taken place, that more and more organizations can come and point and say, 'we have more needs, there are solutions and we want these solutions to be given to us as well'. I am quite sure that 30 years ago it was common for adults with disabilities to have no teeth, and it was uncomfortable and unpleasant, but that's just the way things were. And today implants are something that every person has a right to have in their mouths if they need them, and people with special needs are saying 'we deserve them and we think that we can

49. See note 35.

50. Dafna Kleinman, M.S.W., Director of Outpatient Services at Beit Issie Shapiro.

function better with them.' I think that's the change.

Mona Julius⁵¹ spoke of the impact of this process on the consumer behavior of parents who bring their children to treatment. Today they do not hesitate to bring up needs that once would have been ignored by therapists:

There is a change in the ability of families and the ability of the community to consume a different level of services. Parents used to drop off the child and the therapist was in charge of decision-making about what had to be done. Today there really is a growing demand from families who say 'It's true he needs occupational therapy, but he also has an emotional problem, and helping with that will help him in his studies in class.' I think that this is a relatively recent phenomenon.

In summary, when one begins to see the people with developmental disabilities as whole people who have a right to live with dignity like any other person, one begins to discover in them sides that previously had been invisible. When family members are no longer treated as extensions of professional treatment and are related to as people with their own human needs, it becomes possible to discover and relate to more complex needs. When additional aspects of their personalities have room for expression, totally new directions of professional action and development can emerge.

From Latent to Manifest Abilities

The last vector of change – movement from latent to manifest abilities – BIS began by relating to children and their family members as clients with needs, progressed through working together to promote each child's development, until reaching full partnership in activism for social change.

Maya Goldman⁵² described a basic change in the relations between professionals in BIS and the children and their parents, and compared these relations to those she had known previously.

One of the things that I saw when I got to Beit Issie Shapiro is that it's not a place where parents are opposite the professionals, rather it's the parents and professionals together, confronting the child's problems. And that's a very different relationship.

51. Mona Julius, B.P.T. M.A., Director of Community Child Development Unit at Beit Issie Shapiro.

52. See note 1.

Dr. Louise Kessel⁵³ recalled the change she underwent together with other BIS staff members in her relations with the parents:

We thought a lot about how to relate to the problems of the parents, how to normalize them, how to understand and learn from them instead of blaming them. It really was a very moving process. And this was a new challenge, how to provide services while at the same time enabling parents to feel a part of everything.

Dr. Ruth Raif⁵⁴ noted the insights that these experiences aroused in her:

The experience of being together with the families expanded our perceptions, our knowledge and our insight as professional social workers, to the extent that it became impossible to work any other way. Partnership is something very dynamic and holistic, and it's mutual – it's not just that a professional comes and knows what to do. No, it's this togetherness, enriching one another. Different family members also have what to give, whether the mom or the dad, or other children. We learn so much from them, and the insights are so deep, that is what leads this partnership in the fullest meaning of the word.

Over the years the relations of partnership with family members has extended to include adults with developmental disabilities, and Dr. Benjamin (Benny) Hozmi⁵⁵ described how this process developed in the Special University:

The enterprise of the Special University was born out of the understanding that not all training, aimed to promote the quality of life of people with special needs, has to be directed to professionals, or mediated by parents. Especially in an era with an emphasis upon self determination, it's most important to see what people with special needs can do for themselves.... In the Special University project, our students have joint classes with students in the Schools of Education around the country, in which they discuss issues like learning

- 53. Louise Kessel, Ph.D., Clinical Psychologist, Individual, Couple and Family Therapist. "It has been my privilege to be part of Beit Issie Shapiro since its earliest establishment, including conceptualizing and developing some of the models for helping families coping with disability. I was involved in some of the early staff supervision on principles of family therapy, and since then, my connection has been professional, personal and family".
- 54. Ruth Raif, Ph.D., recently retired from the Ministry of Social Affairs and Social Services, Division for People with Mental Retardation, Head of the Diagnostic Department. Co-Founder of the Social Service in Beit Issie Shapiro.
- 55. Benjamin (Benny) Hozmi, Ph.D., Director of the Trump Institute for Continuing Education in Developmental Disabilities at Beit Issie Shapiro, and a lecturer in the School of Social Work at Bar Ilan University.

disabilities and their emotional consequences. In these shared sessions the participants try to characterize the accessible teacher. The responses to these meetings have been extraordinary, in all aspects. These are always win-win meetings. The Special University students emerge feeling empowered. When people listen to their life experience it frames their lives in a new way, everything that they have gone through suddenly becomes knowledge to be shared, and material for promoting social change. The lecturers say the experience and the unmediated meeting is amazing. It brings first-hand knowledge that is sorely lacking in most professional training.

Finally Dr. Dana Roth⁵⁶ spoke of what she experienced as a radical shift as a result of developing partnerships with BIS graduates in the context of the Scientific Research Project:

In the last few years we have undergone a change in our relationship with our clients, it has taken on a radical direction through engaging with them in participatory action research, a process that engages the client from the very beginning of framing the research question. We have a group from the Special University who formulate research questions related to issues that concern or interest them, and they are full partners in the research. It's true that I have the research tools and methodologies, but they have their world, they know what that world contains, the issues that disturb them, and most important is their interpretation of the findings, they bring understandings that we as professionals lack... From the very beginning I say to them: I am not your therapist and I am not interested in your problems. They really don't interest me. This gives them degrees of freedom that I think they never had, and the most amazing things come up... They led a two-year study of couple relationships among 140 people like them, and the insights they contribute... I very much hope that they have an impact on policy with regard to people like them, and on interventions, and also on how they can lead changes in their own lives... Today I must say that I would never consider doing any study, survey or whatever without involving the population about which I am supposedly going to study.

In summary, in its early years BIS ventured beyond the usual boundaries in the professional relationships it formed with its service recipients. In a dynamic and mutual process it began to discover the people and their complexity, and to move forward together with them on a shared journey toward both an improved quality of life and social change. This journey opened up for all who were involved

56. Dana Roth, Ph.D., Director of Research and Evaluation Department at Beit Issie Shapiro.

opportunities to develop, and also released and empowered abilities that previously had been latent.

Discussion

This chapter provided a description and preliminary analysis of BIS's action strategies on the basis of the recorded recollections of people who were partners at different points in time along BIS's first 30 years. The testimony of those many partners who came to the seminar indeed validated BIS's significant leadership role in promoting far-ranging changes in the area of developmental disabilities in Israel.

In order to place these findings in a broader context, I would like to share a personal perspective. I too have long been one of BIS's partners, a member of the BIS family. My connection with BIS began in the end of 1992, when I joined the staff of a learning seminar facilitated by Professor Jona Rosenfeld and Professor Donald Schon⁵⁷. Prior to the seminar we identified eight projects that we believed succeeded in serving to clients' satisfaction populations that the welfare services tended to serve ineptly and we documented each project together with its director. By then Naomi Stuchiner already stood out for her special leadership and during the seminar she was afforded the title "social entrepreneur", years before this term became popular.

In our analysis of the seminar we identified that each of the projects strove to bring about a change in the relations between the chosen population and service providers, and we distinguished between four different strategies:

1. Providing services to families in the context of the existing service system;
2. Providing services to families from outside of the existing service system with the goal of joining it;
3. Providing services to families through an alternative, separately funded service;
4. Providing services both to families and to existing services while mediating between them.

Each one of the above strategies had advantages and disadvantages. The great benefit of BIS's strategy – developing an alternative, separately funded service – was the freedom to create, to innovate, to set new standards and to work in alternative ways. Of course this freedom depended upon the organization's ability to mobilize

57. See Rosenfeld, J.M. Schon, D.A. Sykes, I.J. (1995). Out from Under: Lessons from Projects for Inaptly Served Children and Families, Jerusalem, JDC-Brookdale Institute.

the requisite resources in order to act as it saw fit. The obvious disadvantage of BIS's strategy was the budgetary insecurity that came from having only a small percentage of its funding come from ongoing government financing.

Already during the learning seminar in 1993, it was clear that Naomi Stuchiner was up to the challenging task of mobilizing the resources that BIS required. It was less clear however whether Naomi would succeed in translating BIS's success as an independent organization into leverage to bring about much broader change in the service system.

Over the years I have followed the development of successful projects in a variety of areas such as welfare, education, mental health and disabilities. Over the course of time it has become clear to me that wonderful projects, that contribute meaningfully to all who are involved in them are the exception but they are by no means rare. In contrast, it is very hard to find projects that succeed not only in carving out limited social spaces in which to practice, but also in bringing about change in an entire social sphere. Before the analysis here it was difficult to even imagine what this might look like in practice.

It is not that many projects don't strive to bring about systemic change. That is an espoused goal of many programs and organizations. Nonetheless, time after time, projects, even if they succeed wonderfully at the level of a limited pilot venture, fail to achieve broad systemic impact. It is as though they consistently come up against a "glass ceiling" that will allow their impact to go only so far and not further. It seems that this "ceiling" is ultimately protected by conservative forces within the service bureaucracies, who tend to take responsibility for maintenance of the existing rules, values, interests, priorities, and practices.

The present analysis, being based as it is upon the testimony of BIS's partners over the years, provides a glimpse at what made it possible for BIS to succeed where so many others fail - in promoting a broad consensus for deep social change. The secret: BIS did not try to break through the glass ceiling. It instead engaged everyone around them as partners in moving aside the glass ceiling so as to discover and create alternative worlds together. And as the years passed, this strategy has borne fruit indeed.

II

Development of Professional Entrepreneurship within Beit Issie Shapiro

Bringing Smiles to Faces: A Revolution in the Field of Dentistry for People with Developmental Disabilities in Israel

Sharon Bacher

Introduction

As always with Beit Issie Shapiro, the need for the Dental Clinic came about from a confluence of coincidences and opportunities within the context of a wider goal of changing the social climate in which dental services are provided.

That there was a need was undeniable. In the 1990's, dental care for children and adults with intellectual disabilities and other severe developmental disabilities, was available only in governmental hospitals and only under general anesthesia. The universities did not provide specialized training for intervention with this population and there were no preventive or educational programs to improve the oral health of people with disabilities. Treatment tended to be crisis-based and did not relate to the aesthetic needs of patients. Such a severely restricted service was pejorative when contrasted to the dental services available to the population at large, which were provided by highly trained skilled practitioners within the community and emphasized oral hygiene and early intervention. Sophisticated interventions and specialties such as periodontics, orthodontics and implant therapies recognized the needs of regular patients not only to have healthy mouths but to pursue aesthetic goals as well.

While there was no law denying treatment to patients with intellectual disabilities and other syndromes, dentists working in private practices avoided treating them. They didn't consider themselves properly equipped to render good services, not having learned how to work with patients who were largely non-verbal, non-compliant, and often presented difficult sensory and behavioral problems. These patients were often disruptive while awaiting treatment and dentists were afraid this might upset their regular patients. And finally, people with disabilities were often poor and unable to pay for private treatment.

For those (mainly adults) living in institutions, dental treatment was provided but oral health education programs were not at a high premium. The focus of care was custodial and managerial and since many of the residents could not learn to clean their own teeth properly or carry out a regular oral health program, their teeth generally received minimal care. Thus patients tended to present themselves at the clinic with severe toothaches, requiring urgent intervention and this usually meant extracting the teeth - mostly under general anesthetic. Thus, in addition to their generally unpleasant lives at the time, having no teeth or ill-fitting false teeth further made the patients look bad and diminished their day-to-day functioning (including eating and talking) and quality of life. According to reports from dentists at the time, very few people with intellectual disabilities had false teeth because of difficulties of patient compliance. For the same reasons, orthodontics or implantation procedures were not given. Lately, with the development of dentistry for people with special needs, implants have become a viable alternative to false teeth and orthodontics provides not only aesthetic solutions but also prevents drooling, crowded teeth and cavities.

Complex social problems are usually the result of the interaction of many events and this was the case with the provision of dental services for people with developmental disabilities. Thus two other factors operated to the detriment of the patients: since there was no specialized training for dentists working with these special populations and the standard of intervention was low and since the patients were unable to advocate for themselves there was little incentive to look for better solutions.

Getting Started

The above was the state of affairs when two South African dentists, Dr. Trevor Segal and Dr. Brian Braude¹, who had immigrated from South Africa - approached Beit Issie Shapiro. Dr. Segal had been seeing patients referred by Beit Issie Shapiro in his private practice after regular hours, in order not to upset his other patients. Since Beit Issie Shapiro had dedicated itself to developing community-based services for people with intellectual and other disabilities, Segal and Braude hoped the organization might be persuaded to work with them in developing a holistic community-based dental service.

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1. As we go to print, we mourn the loss of Dr. Brian Braude who passed away at an early age after a serious illness. In her words at his funeral, Naomi Stuchiner paid tribute to Brian's amazing determination and commitment and his legacy that will ensure that each person in Israel with a disability now has access to specialized dental services.

As Trevor Segal tells the story...

"One day my friend Brian Braude and I were talking about the fact that we had a patient with disabilities and there was no service for him. Some treatment could be obtained at the Hadassa Hospital in Jerusalem, but there was a long waiting list and there was no follow-up care. To make matters worse, it was very expensive. Due to these difficulties, dental care was very low on parents' list of priorities for their disabled children. And back then for private care one had to additionally hire an anesthesiologist – because that's how the treatment was given. He would come with his bag and move the patient to a different room. Most of the dentists in private practice weren't willing to accept these patients, and if they were they didn't know what to do. We decided to help and provide treatment on a volunteer basis. But first we had to find a place where we could work."

Beit Issie Shapiro had been looking for solutions to this problem so that when Segal and Braude approached Naomi Stuchiner, they found a receptive ear. Naomi always had an open mind for exploring new ways of improving the lives of this population. She believed strongly in developing a continuum of community-based services to meet their needs, including their higher social and psychological needs. Naomi was receptive for another reason – she visualized Beit Issie Shapiro as a comprehensive and exemplary service that would not only provide primary and secondary treatment programs but would also be a laboratory where new understanding and knowledge could be generated. This knowledge could then be used as leverage to bring about necessary social and legal changes which would benefit people with special needs throughout the country.

Naomi's response was encouraging. The first thing to do was to survey the children already receiving some service from Beit Issie Shapiro and to ask them about their access to dental treatment. The results confirmed that there was a great need for community-based services of higher quality. A steering committee was set up with people who were moved by the project and who were prepared to put their energies into helping to establish a dental facility for people with developmental disabilities at Beit Issie Shapiro. These included the head of dental services at Meir Hospital, Professor Robert Judeikin, Aryeh Strauss, a volunteer who owned a company providing dental supplies, the late anesthesiologist Dr. Matti Cohen, Harvey Harris, a volunteer who would take care of raising money for the project, and Dr. Chaim Gatt, a dentist who directed and developed the professional program and managed the dental clinic. Later on, Dr. Gatt was employed by the Ministry of Welfare's

Department for People With Mental Retardation to develop its dental services.

In order to fulfill the standards that were set, it was very important to train professionals for this work. BIS therefore set up specialized training programs, including a course to train dental hygienists.

In social entrepreneurial terms, we now had a need, an injustice that demanded to be addressed and stakeholders willing to bring about change. Next BIS looked for financers who might be persuaded to sponsor a fundraising event. The family of the late Shimon Ditkovsky took ‘ownership’ of the dental project and donated their beautiful venue, Gan Oranim, for the first fundraiser, and they continued to support the clinic financially after Naomi Ditkovsky passed away, and through all the subsequent years. Originally named the Shimon Ditkovsky Dental Clinic it was re-named the Naomi and Shimon Ditkovsky Clinic in recognition of Naomi’s dedication to this cause. The Clinic began operating in 1989 and was the first community- based clinic to provide dental services exclusively for people with developmental disabilities in Israel.

Exploring ways to reduce patient anxiety and increase cooperation

Throughout the years there has been an ongoing search for ways of providing treatment with local anesthesia using behavioral and environmental methods to relax patients and gain their cooperation. This presents a special challenge when patients don’t understand the purpose of invasive procedures and are frightened by the clinic’s sights, sounds and smells. Over the years a number of techniques have been developed at Beit Issie Shapiro, including a special ‘butterfly wrap’² made of soft, comfortable material in bright, friendly colors, used to create a papoose around the patient’s body, making him feel secure and comfortable and minimizing random body and hand movements.

In 2007, an innovative research program was undertaken by Michele Shapiro³, the developer of controlled multi-sensory therapy in Israel, as part of her doctoral investigation into the effects of the sensory environment of the dental clinic on patients with developmental disabilities. Among the issues she sought to understand

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2. Developed by Dr. Michele Shapiro
 3. Shapiro, M., Melmed, R., Sgan-Cohen, H. D., Ili I., Parush, S., (2007) Behavioral and Physiological effect of Dental Environment Sensory Adaptation on Children’s dental Anxiety. European Journal of Oral Sciences, 115: 479-483; Shapiro, M., Melmed, R., Sgan-Cohen, H. D., Ili I., Parush, S., (2009) Effect of Sensory Adaptation on Anxiety of Children with Developmental Disabilities – A New Approach. Pediatric Dentistry, 31 (3).

was whether by minimizing noise, dimming the lights and introducing other controlled sensory stimuli, patients might feel more comfortable and relaxed. Based on experience with this method of treatment, the staff of the clinic was also taught to modify their behavior in the clinic, using gentler tones and positive reinforcement to calm their patients.

This groundbreaking research provided many significant insights for designing dental facilities for people with special needs and understanding the role of the practitioner in helping the patient to relax and cooperate. The research was published in highly regarded professional journals, generating considerable interest from academics and practitioners in Israel and abroad and becoming the basis for fruitful professional collaborations. Currently Dr. Shapiro is collaborating with Professor Sharon Cermak of the University of Southern California, in a joint program to assess reduction of anxiety in the dental setting with children with autism.

Treatments provided

The Clinic provides a full range of dental treatment including general anesthesia. An explicit principle of treatment today is that people with disabilities have the right to look as aesthetic as possible because this contributes to their feeling good about themselves, to their self confidence and to their quality of life. An important goal is the improvement of day-to-day functioning (including eating and talking).

Understandably, the range of treatments provided by the Clinic has, over the years, been considerably expanded. With greater ability to gain patient compliance it has been possible to introduce orthodontic and implantation treatment.

Prevention

From the outset, the clinic's goal was to improve oral health, rather than simply treating disease. Since 2004 Dr. Moshe Frank, a volunteer retired dentist, has visited schools and institutions all over the country to assess the oral health of the children or residents and refer them for prophylactic treatment. Moreover, the program provided oral care education and instruction to caregivers and parents and taught them to promote greater independence in the children or adults in their care. According to information from the Dental Clinic, some 4,500 children and adults have been examined since the inception of the program, of whom approximately 30% required treatment. In addition to screening, Dr. Frank and the dedicated team taught the staff at institutions for people with intellectual disabilities how to care for the residents' oral health. Dr. Frank retired in 2010, and Beit Issie Shapiro is looking for a volunteer to replace him.

Improving Standards

The philosophy of Beit Issie Shapiro in general and of the Dental Clinic in particular is not to be satisfied with providing enlightened treatment for the fortunate few, but to share the knowledge with others so that the greatest number of people can benefit. Where necessary this includes working to change the laws of the country. From the outset, the ultimate aim has always been to increase knowledge through systematic research and the ongoing evaluation of patients and programs, and to share the insights thus gained, with other interested parties.

Changing Attitudes

In the early years of the clinic's development, it operated a unique program in which volunteer dental practitioners and anesthetists from around the country were invited to provide free services in the clinic. This had a two-fold benefit, on the one hand keeping costs down and treatment affordable, but more especially, it exposed the professionals to patients with developmental disabilities and afforded them the opportunity to develop skills, experience and confidence. It was hoped that this would make them more accommodating towards treating these patients privately. The success of this program has had a marked effect on a great many dentists, improving awareness of the needs (and rights) of those with disabilities and making good treatment accessible to them.

In 2000, The Shalem Foundation awarded Beit Issie Shapiro's Volunteer Dentists their Yakir Prize, in recognition for the significant impact this program has made on improving the quality of life of people with developmental disabilities.

The prize recognized the outstanding services given by volunteers who, through their work have changed the way Israeli dentists throughout the country relate to this sector of the population. Their experience at Beit Issie Shapiro made it possible for them to develop the skills and sensitivity required to work with people who can't always express themselves verbally. And as they acquired confidence and competence they began to change the attitudes of their colleagues, leading to their increased willingness to provide treatment in the community.

Dr. Mansoor Chalad, an anesthetist from Tira, works at Meir Hospital, Kfar Saba and has volunteered at the Shimon Dental Clinic for many years. Some of his patients have severe handicaps and intellectual disabilities and find it difficult to understand the purpose of the treatment they are receiving. They often object to treatment, requiring work to be performed under general anesthetic. This is where Dr. Chalad's work comes in. "We have patients all ages. Some are brought from the institutions in which they live, by their

caregivers. Emotionally the work is difficult, but when I am there I become so involved that I don't notice the time passing by. It is immensely rewarding to help these patients.

These days, as a result of the initiatives of a small group of volunteer dentists and the staff of Beit Issie Shapiro's dental clinic, people with special needs all over Israel enjoy both effective treatment and preventive oral health care.

Change on a Wider Scale

Over the years, since the Dental Clinic was opened, dentistry for people with special needs has changed significantly. There has been research and there is greater knowledge. One of the important breakthroughs is the fact that Beit Issie Shapiro's Dental Clinic has been recognized by the Health Ministry's Dental Health Division which certifies Beit Issie Shapiro every three years. In addition, the Ministry of Welfare's Department for People with Mental Retardation has worked to raise the standards of dentistry at its institutions and has taken the responsibility to provide dental services in the community. The Health Ministry ruled that only dentists with special training may provide treatment to patients under general anesthesia. Beit Issie Shapiro has been authorized by the Health Ministry's Dental Health Division to run training programs, and they are conducted by the Director of Wolfson Hospital's Anesthesia Department.

As a result of these changes, the Israeli health service providers (HMO's) now participate in the costs of general anesthesia if requested to do so by families and in accordance with each organization's regulations. To help families cope with the high cost of dental treatment, Beit Issie Shapiro operates a Subsidies Committee which provides subsidies for those in need. Akim, the leading non-profit service providing organization for people with intellectual disabilities, has recently taken responsibility on behalf of the government for providing general dentistry to populations with special needs. This has reduced the demand on Beit Issie Shapiro's dental clinic.

Thus Beit Issie Shapiro has been instrumental in catalyzing change in the field of dentistry for people with special needs and today high quality services are provided by organizations throughout Israel. Dr. Udi Yoge, the director of the Shimon and Naomi Ditkovsky Dental Clinic referred to the impact of the Clinic at a seminar which recorded notable changes that have occurred in service provision over the past 30 years:

"I see the impact our little clinic has had on the national level. We have led a number of revolutions in terms of the types of treatments and the style and nature of these treatments. We had to overcome many obstacles from government ministries, the Ministry of Health and the Ministry of Welfare... Undoubtedly there has been a broad long term impact, and the situation today with regard to dental treatment of people with special needs is radically

different from what it was when we began.

"This isn't something that happens in a day. It's a slow process, and I think that today the clinic is already looking to understand the current needs and develop in other directions because more and more services are providing treatment to this population, whereas in the beginning there was a void. And that is one of the necessary outcomes of a long and successful process."

Conclusions

This article has sought to demonstrate how the development of dental services at Beit Issie Shapiro closely followed the theory of social entrepreneurship described by Martin and Osberg⁴ and uniquely combined with the model of community and resource development. Specifically:

- The development was prompted by a need and a deeply felt injustice.
- Thanks to its inherent open-mindedness to new ideas and the belief that all is possible if there is enough determination and skill, Beit Issie Shapiro responded to an initiative by volunteers with a stake in its solution to remedy this need.
- The community development model was used to gain support for the development and provide checks and balances to ensure that it continued to meet real needs. It also focused on dentists' attitudes to people with special needs by recruiting volunteers, providing educational experiences and developing competence.
- The program sought holistic solutions bringing together prevention, the promotion of knowledge, treatment, research and training to improve services.
- Insight without resources is not enough to bring about change. In the case of dentistry for special needs people, the official services were provided largely by hospitals and institutions. In order to change this situation, it was necessary to invest in development. Beit Issie Shapiro recognized that left on their own the authorities would not initiate these changes. Instead private initiatives and matchmaking between an organization with professional resources and philanthropists interested in investing in the development were required. Naomi Stuchiner's skill in finding and forging such partnerships provided the magic to make the dream a reality.
- Most importantly, the visionaries of this program were never content to provide solutions for the few but instead have been concerned with bringing about positive changes for the whole population. This continues to be done through research, training and the publication of attitude - changing information.

4. Martin, R.L., and Osberg, S., (2007) Social Entrepreneurship: The Case for Definition
Stanford Social Innovation Review

Waves of Change – A Hydrotherapy Revolution

Tuvia Stuchiner¹

Before...

In the 1980's, when I was studying Sports for the Disabled at the Wingate Institute, I noticed a number of media items that got me both angry and curious: "Parents of children with intellectual disabilities, especially those with Down Syndrome, reported that they and their children were not allowed into swimming pools in their neighborhoods". The issue of children with intellectual disabilities was close to my heart because of my wife Naomi's role in spearheading the recently established Beit Issie Shapiro. I decided to look into the matter, and as part of my studies I performed a survey of the use of swimming pools by people with intellectual disabilities.

Identifying the need...

The picture that emerged from the survey was quite dismal. It turned out that children with intellectual disabilities had almost no opportunities to enjoy the activity of swimming in a pool, an activity so much enjoyed by their "normal" peers. Their parents abstained from taking them to pools for a variety of reasons: Fear that the pool administrators would not allow their special child entry; that the child, if he would go in, would be the focus of negative attention; that the child might urinate or defecate in the pool and arouse harsh and humiliating reactions; and fear that being in the water might endanger the child, who had never learned how to swim.

Subsequently I learned that, in addition, existing therapeutic pools didn't provide any solution for people with intellectual disabilities. There were very few of these to begin with, and those eight pools that existed operated very minimally within

1. Tuvia Stuchiner is a hydrotherapist who established BIS's Hydrotherapy Center in 1991. He developed and led hydrotherapy training in Beit Issie Shapiro, making it the largest hydrotherapy training center in the world. He is among the founders of the Israeli Hydrotherapy Organization. Tuvia continues to teach in Israel and abroad.

hospitals. Moreover, even those that were specifically intended for use by people with disabilities remained out of reach for people with intellectual disabilities.

From a broader social perspective, it should be noted that in the early 70's there was still a debate within the medical profession, as to whether physical activities really contributed to health. Later, in the 80's, this was no longer disputed, to the point that a lack of physical activities was considered a health risk. But for special populations, such as people with intellectual disabilities, or people who are overweight, there was little if any thought about what might be suitable physical activities. Hydrotherapy was a good solution to answer the above needs because of the characteristics of water such as the weightlessness of the body immersed in water.

The need, then, was blatant and urgent, and the planners of Beit Issie Shapiro's new building in Ra'anana inserted an empty section in the plans with the heading "future swimming pool". Future, for Beit Issie Shapiro in its early stages, meant "when we have money".

Setting up the Therapeutic Pool

First of all: Funding

The first task, then, was finding the necessary funding – first for setting up the pool, and later for supporting its operation over time. The board of directors was understandably wary of the financial burden. We prepared a financial analysis of the operational cost, and expected income. The Trump family from Florida, one of Beit Issie Shapiro's main benefactors, promised its support. Beit Issie applied to the Service Development Fund in the Israel National Insurance Institute for support in setting up a therapeutic pool for people with intellectual and complex disabilities. This was the first proposal of its kind to be received by the Fund. It was turned down.

A rehabilitation doctor, a member of the National Insurance Institute's public committee evaluating the request, claimed that there was no point in investing in a pool that had no therapeutic value, whose only purpose was providing pleasure. Beit Issie Shapiro decided to fight for the equal rights of children with intellectual disabilities, and submitted an appeal that included statements from existing pools for people with disabilities that they were unable to serve children with intellectual disabilities because they were already full caring for people with physical disabilities. The appeal was upheld. The National Insurance Institute gave its blessing and funding to the innovative project. The Shalem Foundation, the Trump family and additional donors added their support. The Finance Ministry made continuation

of support conditional upon a three year analysis of the therapeutic benefits of the pool. In the subsequent twenty years the National Insurance Institute and the Shalem Foundation have supported over 60 hydrotherapy pools in Israel.

For the First Time in Israel: Specialized Design of the Therapeutic Pool

The pool in Beit Issie Shapiro was the first in Israel to be planned in advance as a specialized therapeutic pool. The few therapeutic pools that had been previously built were planned by architects who specialized in building pools in general, and the therapeutic elements were added only at a later stage. In contrast, in Beit Issie Shapiro the therapeutic professionals led the design process from its outset. In order to study the issue in depth, I visited therapeutic pools in Israel and abroad, where I observed others working with people with disabilities. These visits gave me a preliminary understanding of the needs and difficulties characteristic of the people we would work with, and enabled me to learn from the experience – and also from the mistakes – of others.

All of the above led to "out of the box" thinking that gave birth to a number of innovative and original ideas – that were later copied in many other places. At the time it was common throughout the world to build therapeutic pools elevated above the ground. We wanted our clients to be able to go to any pool and feel comfortable, so we decided that our pool should look like a regular pool.

At the same time that we strove for normalcy, we also adapted every detail of the pool to the needs of the special population that would use it: We took measurements to determine the optimal height of a step in the set of steps leading to the water, and we found that steps of a height of 12 centimeters (the usual height is 16-18 centimeters) would enable people who have difficulty ascending stairs to lift their leg to a height of 12 centimeters by rotating their hips, and to go in and out of the pool on their own. To the usual men's and women's dressing rooms we added a third mixed and private dressing room, to accommodate people with disabilities together with their personal aides.

And so, out of our in-depth analysis and the belief that good thinking is the basis for good doing, more and more solutions and innovations emerged: Parents and aides who came with our clients got a special observation area of their own outside of the warm and damp pool area – so that they would be able to sit and watch the treatments in maximum comfort. The pool's offices were placed in a central location to make it possible to monitor the passageway to the pool and also to maintain eye contact with the therapists. On the sides and corners of the pool we installed hand rails at fixed distances from one another. In the transparent windows and ceiling we

installed two-layer Polycarbonate surfaces, a material that provides light, excellent insulation and protection from ultra-violet radiation. The carefully designed acoustics ensured maximal quiet in the pool area – an essential condition for concentration for many clients, especially children with autism. And finally, the dressing rooms were equipped as "practice rooms" in which children with special needs could practice daily activities: getting dressed and undressed, washing, using the toilet, etc.

The measurements of the pool were also determined after much thought and study: Its surface area was 10X20 meters, with its depth ranging in a gradual and comfortable slope from 80 to 135 centimeters, so that therapists could stand confidently while treating the children even in the deepest water. For infants and toddlers we built an additional small pool 6X2 meters and 60 centimeters deep. Many children took their first steps here, with the water neutralizing the force of gravity. Children whom the experts had decreed would never walk, learned to walk here in our little pool.

Taking the Dive

Beit Issie Shapiro's state-of-the-art therapeutic pool opened in September 1991, and very soon the children in Beit Issie's pre-school programs began to visit. It wasn't long before we began to get resistance, and this time from within: The paramedical (occupational, physical and speech therapy) professionals, who had not yet been exposed to the therapeutic advantages of hydrotherapy, were quick to discover the difficulties. One half-hour treatment in the water could often take up to an hour and a half because of all the accompanying logistics: Taking the child out of the class, getting to the pool, undressing, dressing, going to the toilet or changing a diaper – all of these are complex activities for children with difficult disabilities. "Give us another hour of physiotherapy or occupational therapy instead of the pool", the therapists said, "That will be more beneficial for the children". These reservations did not last long, however. The advantages of hydrotherapy became quickly apparent, and many of those who had objected joined the Hydrotherapy course, learned themselves the secrets of water therapy and even fought to add more pool time for their children. At the beginning, hydrotherapy was the last resort for those difficult cases who were not making progress in other therapies. Despite their difficulties, there was progress and achievement which were acknowledged by the medical profession and in many cases, hydrotherapy became the first-choice treatment in orthopedic and neurological problems.

The Virtues of Water as a Therapeutic Environment

People are intuitively attracted to the water. Long before therapeutic professionals learned to make intelligent use of the unique virtues of this wonderful medium, the sights and sounds of water –a flowing stream, a decorative pool or the waves on the seashore - had a calming psychological influence. With time we discovered more and more of the virtues of water, and even discovered that as an environment it provides added value to many therapies usually performed on dry land. Hydrotherapy at its essence is a therapeutic perspective that takes advantage of the special qualities of water in order to support a broad range of processes of therapy and rehabilitation – physical, sensory, communicational and emotional.

What are some of these special qualities? First of all, the specific weight of water is 1- higher than that of a human body which is 0.97, so a person standing in water carries only the weight of that part of his body that remains outside of the water (so, for example, a person who is immersed in water up to his shoulders carries only the weight of his neck and head). Subsequently the water relieves the pressure on the joints, and movement becomes easier. Secondly, water reduces by half the sensitivity to pain, making it possible for the client to significantly increase his range of movement. Water's high density provides support to the body, so that falling in water is slower than falling on land. The soft falling in water, and the longer response time it provides, enables clients to learn how to respond effectively when falling, and this is useful outside of the water as well.

Because of water's viscosity a great deal of strength is required to move and to activate parts of the body. Exercises that are based on this characteristic of water help to strengthen muscles. The hydrostatic pressure of the water makes it easier to exhale from the lungs, and in this way aids breathing. As a result of the hydrostatic pressure on the rib cage, clients who have difficulty making a sound outside of the water can often produce sounds in the water, thereby promoting their speech in therapy. The water envelops, embraces, and touches the entire skin surface, thereby changing sensory experience. Surprisingly, contact with the water has a beneficial impact on people with apparently opposite problems: It relaxes the over-stimulated, and awakens the under-stimulated.

Water temperature in a therapeutic pool, 33-34 degrees centigrade at all times, is slightly higher than the temperature at skin surface in the center of the body. This temperature provides a pleasant sensation and prevents loss of body heat during time spent in the water. This is especially important for clients who have difficulty preserving body temperature on their own while moving. All of these components

cause positive change in the cardio-vascular system.

Finally, the aquatic environment encourages social activity and requires interaction and cooperation. For example, children with intellectual disabilities who usually do not communicate with one another can play in groups or perform joint tasks in the water.

Developing Innovative Treatment Methods

Prior to the 1980's it was commonly believed that merely spending time in the water was sufficiently beneficial for clients. During the 80's a number of methods for treatment in the water began to be developed – mostly for adults with orthopedic problems.

The creativity and initiative characteristic of the story of the pool in Beit Issie Shapiro from the outset, extended to hydrotherapy itself as well. The professional staff in Beit Issie Shapiro believed that it was important and necessary "to help the water help the clients", and that it was up to us to find efficient and effective ways to make the most of its beneficial characteristics. From this perspective we developed a broad assortment of innovative methods in different treatment modalities, and adopted other existing methods. In the field of audiology, for example, staff developed a pioneering method for producing sounds in the water that helped those whose breathing apparatus had difficulty supporting the vocal chords; techniques for treating hypotonic children; and treatments that improved body image and emotional empowerment. Special programs for group work in the water teach children with intellectual disabilities to cooperate with their peers and to overcome fears, for example through swimming in ways accommodated to them. We arrived at a decision that every child treated in Beit Issie Shapiro over an extended time will learn how to swim. With the methods that we developed and with a great deal of patience on the part of the staff, even children with severe intellectual disabilities learned swimming skills, and when a child with intellectual disabilities learns water habits and knows how to swim, his parents aren't afraid to take him on a family outing to a pool.

Therapeutic work in the pool is based on multi-disciplinary collaboration. Pool staff includes professionals from the following fields: Physical therapy, occupational therapy, audiology, therapeutic sport, and pediatric medicine. All of them together provide a broad multi-disciplinary platform for the therapeutic and rehabilitative process of each client. In addition to work with Beit Issie Shapiro clients, this staff also provides professional consultation to therapists in other organizations.

The Growth of Hydrotherapy in Israel

Not long after its opening, Beit Issie Shapiro's new therapeutic pool was already making waves. In the beginning we had only two therapists, I and an additional therapist (Donna) who had been drafted from one of our pre-school frameworks. We soon realized that there was a limit to the number of people that could be treated in one facility, and the answer was to train additional professionals and encourage them to open more facilities in Israel. The worldwide reality was little and limited hydrotherapy training globally, and certainly none in Israel. I decided that in order to be able to treat and to teach, I myself had to develop professionally, thus I traveled to the United States and Europe, taking every possible course available in this field. Soon I became a qualified teacher of many known techniques in hydrotherapy. As demand and workload both expanded rapidly, I initiated Hydrotherapy courses at Beit Issie Shapiro, whose students would do their fieldwork in our pool, thereby also providing support to the small staff. That was what we saw when the first course opened. At the time, none of us imagined how far this direction would take us.

The original program grew rapidly, and hydrotherapy instruction became a core Beit Issie Shapiro activity, as well as a source of income. At first the courses included 40 class hours, but over the course of time they grew to year-long programs of 500 hours and more. Specialized programs were developed for trainees from different para-professional disciplines. From this core the professional theory and practice of hydrotherapy grew, expanding throughout Israel and even abroad, totally changing the face of treatment in water in Israel.

Graduates of our courses returned to their own workplaces and spread the word. They established advanced therapeutic pools throughout the country, with the encouragement and full support of the staff at Beit Issie Shapiro. In contrast to the 1980's, when eight pools operated on a limited basis, now 150 therapeutic pools throughout the country serve thousands of clients. Hydrotherapy has been recognized by the Ministry of Health and even included (partially, for the time being) in the benefits package covered by National Health Insurance. Together with other leaders of the field in Israel, the Israeli Association for Hydrotherapy was established, which I had the privilege of heading for ten years. During that time hydrotherapy became a popular profession taught in many Israeli colleges.

This expansion even extended into the international realm – nowadays Israel is considered to be a world leader in the field of hydrotherapy. Many professionals visit us from abroad to observe and learn. Israeli experts, myself included, are invited to train the next generations of hydrotherapists in Europe, America, South Africa, and elsewhere.

Bringing in the community

One of Beit Issie Shapiro's core values is that children with developmental disabilities and their families have a right to participate fully and equally in the community. One of our strategies over the years has been to invite the community to get to know us and the children in our own facilities, thereby reducing stigma and prejudice. The pool has played an important role in this process.

After a year of therapeutic activity with children and babies we added ambulatory treatment for adults. First we began treating people from the "regular" community with orthopedic problems alongside people with special needs. Subsequently we opened parent-child programs for "regular" babies from the community. The activities were very beneficial to the babies who participated as well as to the relationship between them and their fathers and mothers who were in the pool with them. The rumor spread rapidly – parents from the entire Sharon region began to register their babies for water activity in Beit Issie Shapiro.

This activity was important to us from a therapeutic perspective as well. We treated babies with developmental difficulties, and as therapists we needed to compare them with normal babies in order to learn how regular developmental milestones expressed themselves in water, and how a "normal" baby responds to interventions. We wanted to feel with our own fingers the baby's muscles and movements.

Social integration in the pool was implemented gradually: First there was total separation between the activities of the "regular" babies and the hydrotherapy treatment of children in Beit Issie Shapiro, but as time went on they all began to wade in the pool together. Eventually babies with special needs, such as Down Syndrome, were integrated in the normative groups. In my opinion, this is the height of integration. Parents and babies – with ordinary development and with developmental delays – having fun together in the pool, parents getting to know each other while being and doing things together. These joint experiences have often formed the basis of friendships that extended beyond Beit Issie Shapiro. People who would never have met children with special needs learned to accept them and became friends with their parents in a totally natural way. At the same time, the parents of the children with special needs enjoyed new friendships that freed them from the social isolation often imposed upon them after their child's birth.

The most significant project for bringing in the community was done in collaboration with the Ra'anana Municipality, when hundreds of children from the municipal summer camps came to the pool. The pool was divided in two halves – in one of them the camp children, and in the other half hydrotherapy treatment for the

children of Beit Issie Shapiro. Parents who were worried came in order to see and to ask questions, and the children also noticed the difference between them and the Beit Issie children and asked questions. So we initiated meetings in the camps to explain about special needs.

Following this exposure, people from the community of all ages – not just those with disabilities or various injuries – came to the pool. We overcame stigmas and prejudices, and everyone – from babies a few weeks old till a 92- year-old client, our oldest so far, is enjoying the great benefits of hydrotherapy.

In Retrospect

Almost thirty years have passed since I first proposed the idea of a therapeutic pool. Twenty years have passed since the pool was opened on the Beit Issie campus and began its fruitful activity. Today it can be stated loud and clear: The pioneering initiative that began as a mere dream, radically changed the face of hydrotherapy in Israel. And no less important: The social entrepreneurship of the pool in Beit Issie Shapiro engendered a revolution in the consciousness of Israeli society, and made a major contribution to the acceptance of people with disabilities in Israel. Nowadays children and adults with disabilities are naturally accepted, in the community in general and more specifically in swimming pools. Discrimination has become the exception rather than the norm.

Developing the Snoezelen in Israel – A Personal and Professional Narrative¹

Michele Shapiro ²

The Snoezelen is a therapeutic approach that combines an adapted and controlled physical-sensory environment with a facilitative therapist. The therapist mediates between the client and the therapeutic environment (the multi-sensory room) in order to promote enhanced functioning in the following fields: sensory, behavior, communication, motor and learning.

In this chapter I will describe the process of the development of the Snoezelen in Israel both as a physical environment and as a therapeutic approach. I will present the process step by step and describe how we brought the model to Israel; what changes we made in the model in order to adapt it to suit our professional needs; how we turned the Snoezelen into a national therapeutic approach; how we grounded our experience through an ongoing process of research; how we disseminated the knowledge in Israel and the world; and how we continue to adapt the concept of environmental adaptation to improve the well-being of additional populations.

Like all innovations, this one combined professional knowledge and experience with a personal process of growth and learning. I have chosen to document these processes in order to share them with other professional entrepreneurs, on the assumption that learning from others, has the potential to improve professional processes and to prevent unnecessary frustration.

Like all professional development, this initiative is the fruit of the work of many partners throughout the years, and none of it would have happened without the backing I received from Beit Issie Shapiro, my professional family and home.

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1. Published in: Hovav, M., and Hozmi, B., eds. (2011) From Inclusion towards Full Participation –Challenges and Growth over the Life Span, Rotem: Givataim (Published in Hebrew).
 2. Michele Shapiro, Ph.D., occupational therapist, Manager of Multi-Sensory environment and specialist of sensory adaptations.

Personal Introduction

The turning point in my professional life took place seventeen years ago. I was a veteran occupational therapist and most of my professional experience had been in the field of children with learning disabilities. I loved my work and it gave me a good feeling to be able to help the children who made progress following my professional interventions.

In 1987 I decided to join the staff at Beit Issie Shapiro and to work with children with intellectual disabilities. After a process of learning, getting to know the new population, and adjusting to the organization, I felt increasing frustration. I realized that I had no answers and that I lacked the tools needed to make a difference. I tried all of the methods I knew and none of them felt right. I began to ask myself hard questions such as "How can I keep working with these children if I have no way to communicate with them?"

I took a child into the therapy room and instead of treating him I found myself arguing with God. "Why did you create people like this? What kind of quality of life can they have? How are parents supposed to cope with this pain?"

Naomi Stuchiner, a pioneering social entrepreneur who was then the Executive Director at Beit Issie Shapiro and a long-time friend, encouraged me to broaden my thinking and look for new ways of working that could be more effective. She pushed me to "think out of the box". And so I embarked on the exciting personal and professional journey that I continue to this day.

While routinely looking through catalogues of therapeutic equipment, I discovered a picture of moving colored lights in a dimly lit room, and I felt my stomach flip. I had the sense that I had found a new direction. I asked myself: What is this thing? It was a room with different kinds of lighting effects, music, and white mattresses and I wondered what kind of effect it might have on our children?

It seemed a magical place that I myself might love to visit. Just from looking at the picture of the space I experienced a feeling of peace and at the same time excitement. As a person with hypersensitivity I often feel overwhelmed by sensory stimuli that make me feel extremely uncomfortable. This room, I thought to myself, could be a safe place for me. It was partially dark, hiding unnecessary visual detail other than exciting bright lights that seemed to have their own slow sequence. It looked soft and inviting with its white backdrop, and it was devoid of clutter. The title of the picture of the room was "Snoezelen".

I read that the room was built in order to provide a place for leisure time activities

for adults with intellectual disabilities. They enjoyed varied stimulation: the changing colors, the diverse scents, the variety of sounds and tactile sensations.

I immediately felt that this sensory environment could have therapeutic potential for our children in Beit Issie Shapiro. I wondered whether spending time in an adapted sensory environment could be therapeutic in itself. I could think of a professional direction in which we adapt the environment as a treatment plan with measurable functional goals for each child, like using this environment for a person who is oversensitive to sight. Due to the control of stimuli in the room we can offer differing levels, intensities and kinds of lighting effects. The person can get used to the stimuli in the room at his own pace, before we help him get used to stimuli in the regular environment outside of the room where control is not available.

Naomi Stuchiner opened the door and paved the way for the next stages. We, the staff at Beit Issie Shapiro, were on the threshold of a new and fascinating breakthrough. We were excited, but still we did not know where we were heading.

We decided to begin with an in-depth study of this kind of facility and its uses. I traveled to the Netherlands to meet Ed Verheul, developer of the room, and to see him at work in the Hartenberg Center in Northern Holland, an institution which houses adults with intellectual disabilities. I sat in the room for days on end, watched the activities and felt the bodily sensations. I asked others and myself many questions. From there I went to England and visited Whittington Hall in Chesterfield, where a "Snoezelen" – as the room was called - had been built in an institution for people with intellectual disabilities. The approach was similar, and once again, I spent many hours watching and asking questions and learned a great deal through personal experience and reflection.

I also learned about the types of special equipment used in such a room and visited the companies that produced this equipment. Both of the institutions that treated a similar population used the rooms to facilitate relaxation and leisure. On my way home, I reflected the different needs and wondered how I could use this type of stimulation as an excellent treatment room for our children. However, how would we fund this development? It was clear to me that we would have to find partners to share our planning and to finance the setting up of a room at BIS and our experimental efforts to learn how best it could be used.

As an organization, Beit Issie Shapiro has always been good at mobilizing partners to join and support social change and innovations for the benefit of children with intellectual disabilities. In order to make a change of this magnitude we needed to find at least one partner who would pave the new way.

In 1993 we succeeded in contracting with the Wolfson Family Charitable Trust,

to help set up the first Snoezelen room in Israel. As part of their agreement, the Trust stipulated that we must carry out empirical research to measure the effectiveness of therapy in the room. With our wonderful new room, we now began working with children in it. We paid close attention to each child's every movement and expression in the room, noting their emotional response and level of reaction as well.

Although we believed in what we were doing, we had to cope with a considerable amount of criticism that came our way. Many people said "the room can't be effective", or accused us of being faddists, saying that "this is just a bubble that will burst". Nevertheless, our experiences with the children soon showed that we were onto something important.

In order to bring to life what we went through in that first year, I have chosen to present the story of Aviv, one of the first children treated in the room.

Aviv's Moving Journey

Aviv was ten years old, with curly hair and big eyes and severe intellectual and behavioral disabilities. He moved constantly, never stopping, frequently bumping his teachers and the children in his class. He would climb wherever and whatever he could. He especially loved to walk along the windowsill. His caregivers always had to have an eye on him because his energetic behavior often put him at risk.

I had a detailed professional evaluation of Aviv's abilities with a long list of his therapeutic goals, one of them being to teach him to put his shoes on by himself. I had treated Aviv in the occupational therapy room and had never succeeded in getting beyond his behavioral problems. I was very frustrated. I was so focused on my therapeutic goals that I never stopped for a moment to think about Aviv's own distress and needs. I didn't try to understand why he needed to be in constant motion and instead I tried to curtail his movement, his bumping into people and his constant touching of things.

Aviv was one of the first children to visit the new Snoezelen room at Beit Issie Shapiro. I decided that since he was a hyperactive child it was important to offer him a room with low-level stimulation, so I was very careful in turning on the various stimuli in the room one at a time. For example, I started with the bubble unit – a vibrating Perspex cylinder filled with liquid and bubbles that changes color. Only after that was switched off, would I turn on the 'vibrating pillow'. In our first sessions, Aviv behaved exactly as he did in the occupational therapy room. He spun around like a spinning top, falling and getting right up. My heart stopped beating. It

looked like I had failed to help him. It was terribly disappointing; everyone around me was looking for successes and outcomes and it seemed that our new method did not help.

Then in the fifth session I decided to try a different way – I turned on all the lights. Now Aviv found himself in a veritable wonder-land. The room was transformed by moving light effects of different colors and shapes. I also introduced music, vibrations, and more. Aviv's response was amazing. He stepped into the room slowly and carefully, not in his usual manner and measuring each step, approached the waterbed. He sat down gently, took a giant pillow, covered his legs and stared at the lights with wonder. He sat focused, motionless, not moving from that spot, tracking the movement of the lights. The thought came to me that there had been a reversal of roles between Aviv and the room: now the room had become 'hyperactive' while the child sat and watched. Aviv was finally able to rest. Did the room somehow take over some need from him, allowing him the respite of rest? What did it all mean?

I was totally surprised and ran to share my excitement with the class staff. His teacher and I watched Aviv from the doorway and we were moved to tears.

This was of course a very significant turning point for Aviv, his family, the staff, and the world of Snoezelen. Aviv continued coming to treatments in the room. We found that he was able to enjoy a break from his hyperactivity and to rest. During the time that he was in the room and for the half hour afterward, we took advantage of his focus in order to work with him on learning skills. (Aviv began to put on his shoes by himself as well as to do other activities from the goals set in his original treatment plan).

Aviv's family was invited to see Aviv in the room and this too was a moving moment. After discussing the significance of the change they saw in him in the Snoezelen environment, they decided to add more and more stimuli to his bedtime routine, such as adding bubbles to his bath, placing a rotating lamp in the washroom, and playing background music with changing rhythms. According to his parents, after making these changes, Aviv became much more manageable at home.

It was at this stage that we began to understand that the environment was having far-reaching effects upon the behaviors of our children, far more than we had realized, and that this could be purposefully adapted to improve their functioning. We understood that the environment would have a particularly significant effect if we could understand the sensory needs of the child and provide him with just the right dose of stimulation. The amount, type, and magnitude of necessary stimuli differ greatly from child to child and from adult to adult, and for each person – from hour to hour and from day to day. Most people adapt to their various environments

and are able to filter stimuli that bother them. Children and adults with special needs need help in adapting to their environmental stimuli.

Validating our Impressions with Research

We accumulated experience and knowledge from our many treatments. At that stage, I was the only therapist in the room. It was difficult not having anyone with whom to reflect and to share feelings, but there was an advantage. The great deal of time I spent in the room enabled me to concentrate, to observe and to "be" with the child. Just when I felt that I had made the most of this stage and was ready to move to the next, I found a partner – a special education teacher who had worked in a Snoezelen room in England but had recently immigrated to Israel and came to see Beit Issie Shapiro. We invited her to join our team and the very next morning we began to work together.

In 1995 we carried out our first empirical research to study the efficacy of the Snoezelen to reduce maladaptive behaviors and facilitate adaptive behaviors in children with mental retardation. Our findings were published in 1997³.

We were looking to answer the question of how effective the Snoezelen was in the treatment of children with intellectual disabilities. This research was carried out in collaboration with the Department of Occupational Therapy in the Hebrew University and with the Lowenstein Rehabilitation Hospital in Raanana. It provided us with our first tentative answers.

In the study, we assessed 20 children between the ages of 5-10, all with moderate to severe intellectual disabilities and with maladaptive behaviors. The study was performed in the Snoezelen room, and for comparison in an occupational therapy room. We videoed the children in both rooms and we measured their heart rate by connecting them to an ambulatory "Holter". Two volunteers were trained to code the videos in order to identify the maladaptive and adaptive behaviors. Each volunteer coded the videos independently. The high correlation between the coders demonstrated the reliability of our behavior tool. The results were very exciting! We found a significant reduction of maladaptive behaviors and an increase of adaptive behaviors in the Snoezelen room as compared to the occupational therapy room.

The "Holter" assessment reinforced our findings. The heart rate of children with

3. Shapiro M., Parush S., Green M., Roth D. (1997). The efficacy of the Snoezelen in reducing maladaptive behaviors and facilitating adaptive behavior in children with mental retardation. British Journal of Developmental Disabilities: 43: 140-153.

intellectual disabilities and hyperactivity was found to decrease, while there was an increase in heart rate among those with intellectual disabilities and passivity. This finding led us to another important insight about the room.

It appeared that children react differently to stimuli. Some are overwhelmed and are unable filter too much of a particular kind of stimuli. Those children tend to be hyperactive, and the Snoezelen room calms them down. In contrast, there are children who have little response to stimuli in their environment and tend to be passive. However, the stimuli in the room seem to arouse both groups. The children become more focused and improve their functioning.

Aviv, who was one of the subjects in the study, exhibited a decrease in heart rate. In addition, a decrease in hyperactivity was noted. This explains why when all the stimuli were activated in the Snoezelen room he was able to calm down.

Nimrod was 9 years old at the time that the research was carried out – he had moderate intellectual disability and was extremely passive. He could not speak, and communication with him was limited to a number of signals and gestures. He was a loner and played by himself. Most of the time he looked downwards and seemed indifferent to his surroundings. The very first time I took him into the Snoezelen it was as though he had awakened from a dream. His head perked up, his eyes opened and he began looking around like an explorer. He was also one of the children who participated in the study. His “Holter” test results showed that in the room his heart-rate increased.

The results of the “Holter” test for the whole group of children showed either an increase or decrease in heart rate. In other words it suggested that it might be possible to balance the heart rate by being in the room, and that this experience in itself could be therapeutic. When we understood this, we realized that the Snoezelen approach could be suitable not only for the children at Beit Issie Shapiro but also for other populations.

In 1997 we published the article with the results of our study. It was the first empirical study of the effectiveness of therapeutic interventions in the Snoezelen room, and it was published in the British Journal of Developmental Disabilities.

Disseminating the Knowledge in Israel

The next stage in the process was to disseminate our new knowledge to our colleagues in various fields. After some consideration, we decided that it would be right to start with policy-makers in order to obtain the professional, administrative,

and financial legitimacy to implement the Snoezelen as an effective therapeutic approach in Israel. We tried to identify the governmental systems that would be able to lead the change. We turned to the Ministry of Education, the Ministry of Labor and Social Affairs, the Ministry of Health, the National Insurance Institute, and the Shalem Foundation. It took several years of collaborative work with the ministries until, in 2000, the Ministry of Education issued detailed rules and regulations for working in the Snoezelen room, thus accepting it as a facility of value in the school setting. The Ministry policy obligated teachers to take an introductory course on the Snoezelen approach. This was the first step in turning the Snoezelen into a therapeutic approach, in contrast with the international model which saw it almost exclusively as a venue for leisure activity. The effects of this directive soon became apparent as different educational and treatment frameworks in the community began to open Snoezelen rooms, first for children and adults with intellectual disabilities, and then for additional populations.

In 1997 Beit Issie Shapiro - having taken upon itself the mandate of sharing the knowledge with others - opened its first training program. Collaboration with the ministries led to an increase in demand for the courses, and despite the difficulties in financing, we had enough interest to fill three courses a year.

The “knowledge development” process was itself interesting. Since we were developing a new therapeutic approach, we needed to find a theoretical ‘home’ to provide a conceptual basis for our treatment. The roots of our knowledge and understanding of the impact of controlled multi-sensory stimulation (as the technique came to be known) arose from our intensive period of observation, and trial and error learning. Our first training program was developed by asking ourselves what we knew that enabled us to work well in the Snoezelen room. The answers to this question we translated into course topics: The Snoezelen room and its components, observation of the senses, the connection between sensation and emotion, how to be a facilitating therapist, learning about the children we care for and their particular characteristics, music and its influence on the clients, the influence of the physical environment on behavior, and more.

In each course, we re-examined the outcomes, relating to all the written feedback we received from the participants, and we repeatedly adapted the course contents and its emphasis until we finally developed an approach and a body of knowledge. The essential components of the approach seemed to depend on the communicative style of what we called the “facilitative therapist” working in an adapted environment. To this day, we continue to develop our knowledge, with participants in each course providing feedback that generates new learning.

In 2000, a donor from the United States visited Beit Issie Shapiro. He took a great interest in the Snoezelen approach and asked what he could do to help us to develop it. We told him that rooms were being opened throughout the country but that few people appreciated that they needed training to be able to exploit the rooms' potential. Moreover, many of those who would have liked to do the training program couldn't afford to pay. Our farsighted donor, The Lorraine White Foundation, took on the responsibility for subsidizing the training of all course participants in Israel, and also to fund our further research and knowledge development. This initial investment made a huge impact, generating a great deal of interest and excitement, and turned The Lorraine White Foundation (through which the donation was given) into a committed partner. The Foundation became the 'adoptive family' of Snoezelen in Israel and their substantial and dependable investment over a period of almost 11 years, gave us the opportunity to become leading innovators, researchers and educators in this method.

We had no idea there would be so great a demand for the course and so much interest in the Snoezelen method. Participants were professionals from different fields, such as special education pre-school and school teachers, caretakers and aides from nursery schools, rehabilitative day-care settings and institutions, nurses, social workers, psychologists and expressive therapists and other Allied health professionals. The growing diversity of uses of the method led to greater insights and understanding. Ed Verheul's concern that turning the Snoezelen into a therapeutic tool would make it the exclusive realm of occupational therapists turned out to be unwarranted.

The professional model of the Snoezelen was first developed for the children of Beit Issie Shapiro and our courses were always based on examples drawn from our work with the children. However, with the expanding numbers of Snoezelen rooms and practitioners, we were able to draw examples from different populations and today our courses are replete with case studies drawn from working with people with dementia, the elderly, severely ill children, adults with intellectual disabilities and more.

In the years to follow, we also developed specialized courses by working in partnership with therapists from other organizations. For instance, we developed a course with the staff of the Schneider Children's Medical Center for hospitalized patients, a course for Snoezelen with the elderly in partnership with the staff of Shaarei Tzedek hospital, a course for Arabic professionals working at the Sacred Heart Institute, courses for the treatment of trauma (in response to the need in Sderot when it was the target of Kassam rockets, and in the north during the Second

Lebanon War). The knowledge we developed from our courses was described in our first Snoezelen Handbook, published in English (2002) and translated into Hebrew (2004). The book was disseminated among students in our courses in Israel and sent abroad to interested parties.

Disseminating the Knowledge and the Approach in the World

In parallel to its development in Israel, knowledge about the Snoezelen spread from Holland and England to additional countries throughout Europe, the United States, Canada, Australia, China, and more. International conferences began to be organized and I was invited to lecture and to present the unique Israeli model. Later on, we were excited to be invited to open a Snoezelen training program at the Jackson Memorial Hospital in Miami. The Director of the Neurotrauma Unit, Dr Gillian Hotz, had visited the MacMillan Hospital in Toronto and had seen a Snoezelen room there, and on enquiring where she could learn more about this, she was told that Beit Issie Shapiro in Israel are the experts. She believed that the approach might be good for her patients who have incurred brain injuries.

Their course was targeted at Allied health professionals. We were pleased to share our own knowledge and experience from a previous course in the field of traumatic brain injury that took place in Beit Lowenstein some years before. The Miami team later carried out research on the helpfulness of the approach and found that Snoezelen therapy reduced irritability and resulted in improved attention and concentration – which was similar to what we had found at Beit Issie Shapiro.

This first training program in the United States launched our dissemination to other parts of the world. We have subsequently presented our knowledge at conferences and courses, and representatives from many countries have come to Israel to learn from our training programs and present at our international conferences.

One of the most fascinating meetings I have had in international conferences was with Dr. Temple Grandin. Dr. Grandin was born with autism. Nevertheless, despite her difficulties, she graduated as a PhD and has become a professor of animal science, an inventor, and a prolific writer on the subjects of animal science and autism⁴. I met her at a conference in the United States and invited her to present a keynote address at Beit Issie Shapiro's First International Conference in 1994. Her lecture at the conference was fascinating and opened a wide door of insight into the

4. Grandin T., Johnson C. (2005). *Animals in Translation*. New York: Scriber, 27-241.

world of people with autism. On seeing the Snoezelen, Dr. Grandin suggested that the Snoezelen might be effective for her because the stimuli in the room are the same stimuli that exist in her head at all times, making it difficult for her to concentrate. When she sees these stimuli outside of herself and in the room, it seems to empty her mind and make it possible for her to focus better. This was the first time that we heard an adult with autism explain from her vantage point, what we had tried to understand from our work with Aviv all those years ago. We were very grateful to Dr. Temple Grandin for giving 'voice' to the experiences of our children.

Leaving the Room and Creating New Learning Models

Temple Grandin's visit encouraged us to take our sensory ideas out of the Snoezelen room and see how we could generalize the knowledge we had gained in the Snoezelen, to improve our children's total learning and treatment milieu. In her groundbreaking work, Temple Grandin had changed the design of livestock buildings to reduce the stress of the cows on their way to slaughter. By leading them through a special walkway and reducing the smell and sounds from the slaughtering pit, she was able to reduce the stress for the cows and make the whole slaughtering process more humane.

We knew that just a few hours of treatment in the Snoezelen room often had an impact outside the room as well and began to ask ourselves how factors such as lighting, color and acoustics affected our children's well-being and ability to learn. Taking advantage of a large scale renovation and expansion of our premises, we began to create a more accommodating environment. We also began to install features of the Snoezelen in other treatment rooms including our hydrotherapy center and the dental clinic. Each development was accompanied by a program of observation, and ongoing evaluation of its impact.

At this stage, we embarked on a study of "lighting" carried out in collaboration with professional lighting consultants, Epidemiology experts from Rambam Hospital and experts from the Ministry of the Environment. 30 children aged 1 ½ to 3 years were studied. They were randomly divided into two groups. Group A spent a week in the typical classroom lighting while carrying out activities (typical down facing fluorescent lighting with inert flicker and hum) and the following week the children did the same activities while under a new and improved fluorescent lighting which was up-facing and had no flicker nor hum. Group B did the same activities but in the opposite direction of lighting. The children were filmed by video and their behavior was coded. Findings of the study proved that in the conditions of

the improved adapted lighting the children exhibited less maladaptive behaviors, more adaptive behaviors and the noise level (crying, shouting) reduced. In addition, levels of cortisol in the children were measured from their saliva. Research results were published in the Journal of Intellectual Special Needs Education⁵. The positive research results led to our adapting and changing the lighting in Beit Issie Shapiro and to our advising colleagues in various frameworks to adopt the new way of lighting.

Hydrotherapy is a popular form of treatment at Beit Issie Shapiro since water is a powerful sensory stimulus for our clients. Nevertheless there are many children who have difficulty adjusting to the regular hydrotherapy pool. Their difficulty is compounded by the noise and unexpected movement of many people being in the pool simultaneously. After our study, we made adaptations to a second secluded hydrotherapy pool, giving the clients an opportunity to slowly become accustomed to the water at their own pace. We reduced the amount of lighting in the area, added optic fiber effects in and out of the water for them to look at, and colored lighting and music both under the water and in the pool environment. This process was accompanied by case studies which compared the outcomes of treatment of three children treated in the adapted hydrotherapy pool as compared to their treatment in the regular pool. This study was published in the International Journal of Adolescent Medical Health in 2005.

Another physical environment that posed a great challenge was the dental clinic. Many children and adults are anxious about visiting the dentist. This is even more so for people with special needs. According to the parents and caregivers, when the children knew they would be visiting the dentist at Beit Issie Shapiro, they began crying and resisting as soon as they pulled up in our parking lot. I thought by applying some of the adaptations from the Snoezelen to the dental environment we might be able to lessen the children's trauma. Thus began our next project for research. I decided to take it on as the focus of my doctoral research program. Having the backing of an academic setting afforded us the involvement of the Schools of Occupational Therapy, Dentistry and Medicine of the Hebrew University, and the School of Dentistry of Tel Aviv University.

For two years, we worked on designing the dental clinic in an innovative way that included sensory elements similar to those in the Snoezelen room. We removed all simple fluorescent lighting and replaced them with soft colored reflective upward facing lighting that had a dimming effect. We added a number of lighting effects

5. Shapiro M., Roth D. and Marcus A. (2001). The Effect of Lighting on the Behavior of Children who are Developmentally Disabled. DISSES Journal, Vol 4, 19-23.

with slowly changing colors in the area directly above the patient's eye view. We connected speakers to the dental chair and played music through them, giving the patient a vibro-acoustic experience. In addition, we designed a friendly "butterfly" that fitted on the dental chair and hugged the patient during the dental treatment.

Our sample group of 30 children with special needs was divided into two random experiences. Each child received two types of dental treatments with a gap of four months between them. The first group received the first treatment in the dental clinic without multi-sensory stimuli, and the second in the adapted dental clinic. For the second group the order was switched. This cross-over design was carried out in order to neutralize the effects of the treatment sequence.

Each treatment was videotaped and objective observers coded the maladaptive behaviors (such as refusal to cooperate, biting, loud crying, etc.). The amount of sweat on the skin surface was measured as a sign of stress by an electro-dermal instrument that was connected to a computer and produced a graph showing the levels of anxiety and relaxation. The findings unequivocally favored the clinic with the sensory adaptation, in terms of both the behavioral and physiological measures.

At this stage it was decided to add an additional group to the study (children with normal development) to see if the change in the physical environment would also be beneficial for children without special needs. The process was repeated, and the results were again positive, though the difference was less dramatic than those for children with special needs. One explanation for this might be the fact that the 'normal' group has in addition to a sensory-emotional process, a cognitive process that influences the outcomes. Our findings were published in three articles in international journals: European Journal of Oral Medicine⁶, Dental Pediatrics and Journal of Pediatrics⁷.

Publication of the articles brought new partnership opportunities for us at Beit Issie Shapiro. One of these is the University of Southern California in Los Angeles where they have decided to expand this research. They invited me to present as a keynote speaker at an international conference in February 2011. This partnership has generated an increased interest in the Snoezelen in the academic world, as well as coverage in the international media.

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6. Shapiro, M., Melmed, R.N., Sgan-Cohen, H.D., Eli, I., & Parush, S. (2007). Behavioral and physiological effect of dental environment sensory adaptation on children's dental anxiety. European Journal of Oral Science, 115: 479-483.
 7. Shapiro, M., Melmed, R.N., Sgan- Cohen, H.D., & Parush, S.(2009). Effect of Sensory Adaptation on Anxiety of Children with Developmental Disability- A New Approach. Pediatric Dentistry, 31, (3): 117-123.

Accommodating the Environment for Clients with Additional Special Needs

In our work with children in the Snoezelen, we became aware of a unique recurring phenomenon in which some of the children persistently gravitate towards equipment that has a black background (black background with lighting effects), and systematically moved closer to these apparatus. After observing this phenomenon for several years, we hypothesized that these children were responding to the strong contrast between the dark background and the bright lights. We decided that this was not a random occurrence and wanted to understand what was going on. This led us to design our first dark room⁸. This is a room with dark walls (dark purple) and with a dark close cut carpet on the floor. It also has a dark blue ceiling with twinkling stars. This room has a very high level of visual contrast. Our therapeutic approach did not change, but we allowed our children to spend time in this differently adapted room. Following a period of adjustment to the new room some interesting facts began to emerge. It seemed that the autistic children preferred the dark room, while the children with Rett Syndrome preferred the white room. Similarly the children with cortical eye impairment (an undamaged eye, but a difficulty decoding what is seen) preferred the dark room. We consulted with experts in the field and we got answers – the children with the cortical impairment need the initial contrast in order to practice prior to seeing. Afterwards they could be exposed to higher degrees of light, until they spontaneously used their visual capacity. The children with Rett Syndrome are afraid of the dark because many of them are afraid of movement. It is important that they see exactly where they are going. In addition, the girls rely on eye contact. They do not speak, but they communicate with their eyes, and therefore they need light. In contrast, autistic children do not like to make eye contact. In the dark Snoezelen room one can barely see the other's eyes, and this makes it possible to improve communication at the rate suitable to the client. We are planning a new experiment to test our hypothesis.

It is still clear to us that every child and adult has unique needs with regard to multi-sensory stimulation, unrelated to their belonging to a specific disability group, and these needs change at different stages of development. For this reason when we opened the dark room, we thought to remind our staff members to always keep their eyes open to understand the unique needs of the individual child.

8. Shapiro, M., Sgan- Cohen, H.D., Melmed, R.N., & Parush, S. (2009). Influence of Adapted Environment on the Anxiety of Medically Treated Children with Developmental Disability. *Journal of Pediatrics*, 154: 546-550.

Development Creates Change and Hastens Processes and Challenges Toward the Future

Since bringing the Snoezelen to Israel, a large and tight network of professionals and organizations working with the Snoezelen has been built. Today other organizations and professionals are also taking the knowledge in new directions.

There are many examples. I will relate to a few of them

- Development of the Snoezelen in the area of geriatric rehabilitation – a veteran occupational therapist learned in our course, returned to the hospital in which she worked and developed extensive knowledge in this area. Today she is part of our staff of facilitators, where she shares the knowledge she has acquired with other organizations.
- Psycho-geriatrics – was developed in a psychiatric hospital and studied by psychiatrists and occupational therapists. It was proven to be an effective alternative to restraint.
- Deafness and hearing disabilities – an audiologist who attended the course brought the Snoezelen room into the treatment of deaf children and youth who are deaf, on the assumption that people for whom one of the senses (in this case hearing) was lacking could enjoy stimulation of their other senses. In this area too there is room for research and additional knowledge development.

In each of the above areas we were not the initiators or leaders, but we are interested in their findings and willing to help in accordance with Beit Issie Shapiro policy.

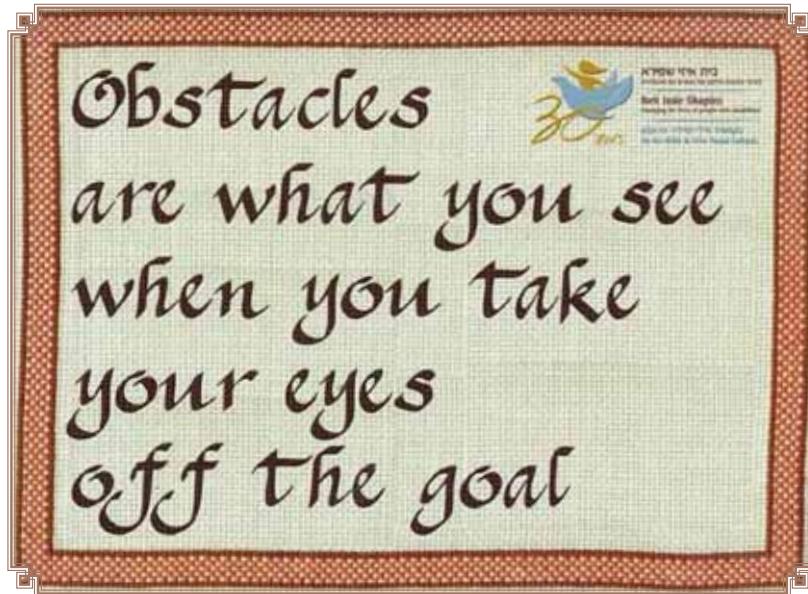
In the beginning, our purpose in building the Snoezelen, was to find new ways of enriching and treating the children in our care – who often did not respond to traditional methods of intervention. Today the Snoezelen environment is characterized by different challenges and applications.

In addition, graduate students from different universities are doing research on many other aspects of Snoezelen. For instance, one group of students is interested in the change in therapist attitudes toward clients as a result of the Snoezelen course, the effect of color on behavior, clarifying which effect has a greater impact on a client.

Our future plan is to establish a consulting center for participants who are working in the field, an interactive website with newsletters, questions and answers, a center for research and a global learning experience.

III

Pictorial History of Beit Issie Shapiro





Issie Shapiro: 1915-1980



With a resident of the
Selwyn Segal Hostel
in Johannesburg

It began in 1980, after Issie Shapiro passed away suddenly. He and Lucie Shapiro and their children, had earlier made aliyah to Israel and wanted to contribute to improving services for children and adults with developmental disabilities.

Issie had always been committed to the community and in South Africa was one of the founders of the Selwyn Segal Hostel and the Avrille Elizabeth Home for children with intellectual disabilities.

Lucie Shapiro: 1914 - 2005



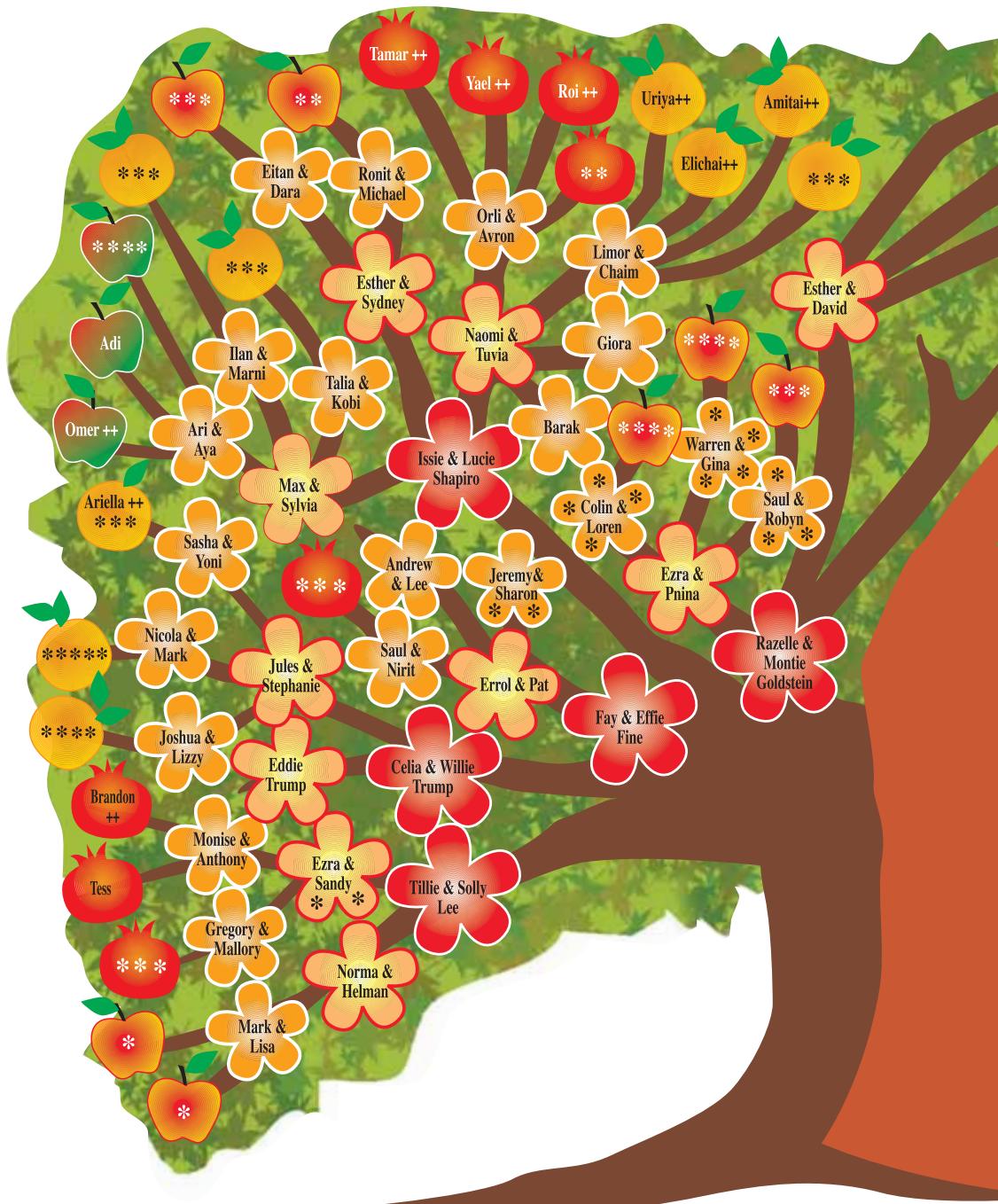
“Chesed” - giving – was a deeply cherished value in the Shapiro family. In 2006, the grandchildren of the extended Shapiro family, dedicated a therapy room at BIS, in memory of their grandparents, affirming their acceptance of this heritage and their commitment to Beit Issie Shapiro.

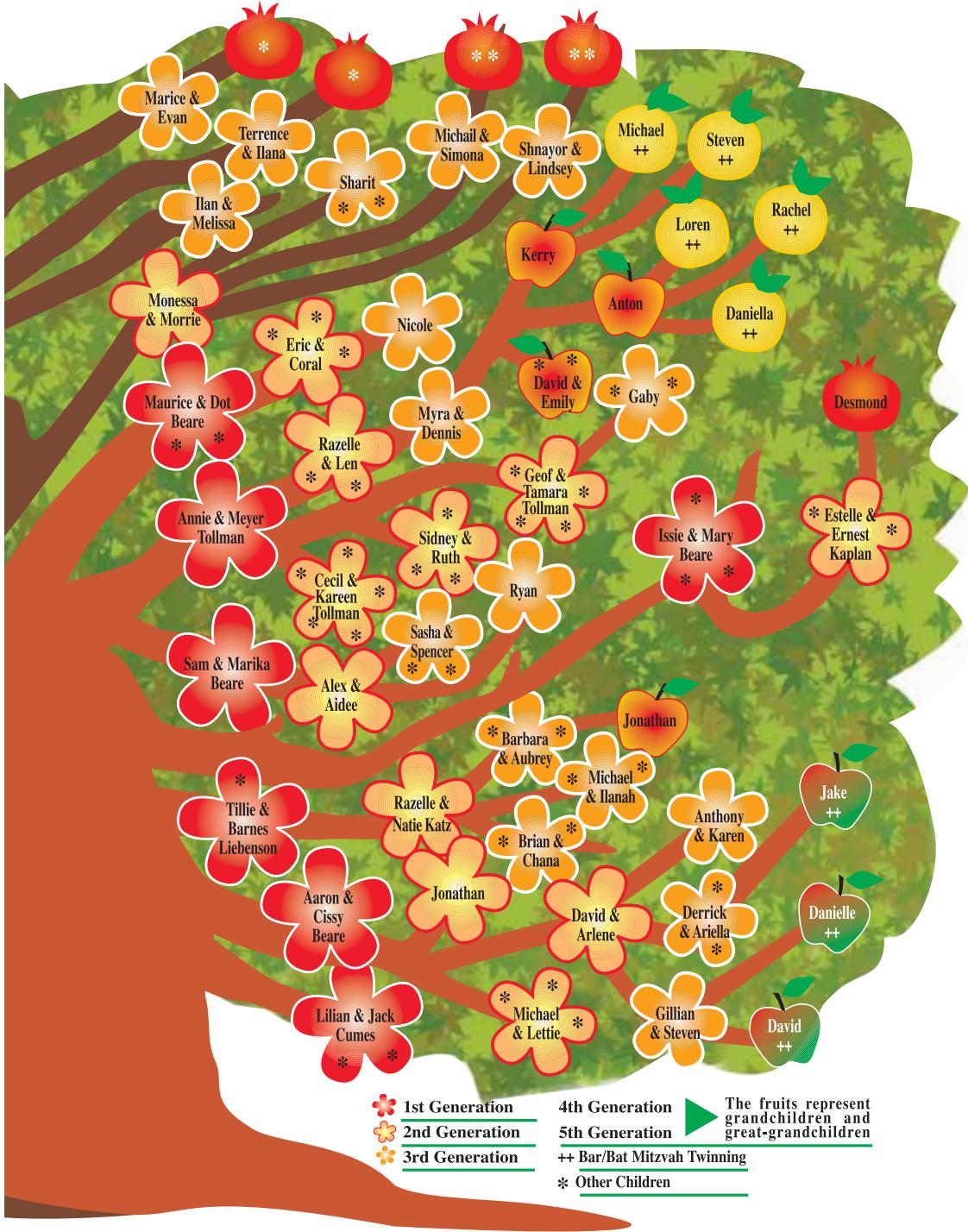


Max Shapiro, Esther Boyd, and Naomi Stuchiner, together with the grandchildren and great-grandchildren proudly admire the plaque dedicated to their grandparents in the therapy room



FAMILY INVOLVEMENT IN BEIT ISSIE SHAPIRO







Naomi & Tuvia Stuchiner with their children, Orli & Avron, Limor & Chaim, Giora and Barak



Their ongoing involvement and commitment to BIS is a great source of pride to the children and grandchildren of the late Issie and Lucie.



Max & Sylvia Shapiro with their children, Ari & Aya, Ilan & Marni and Talya & Kobi



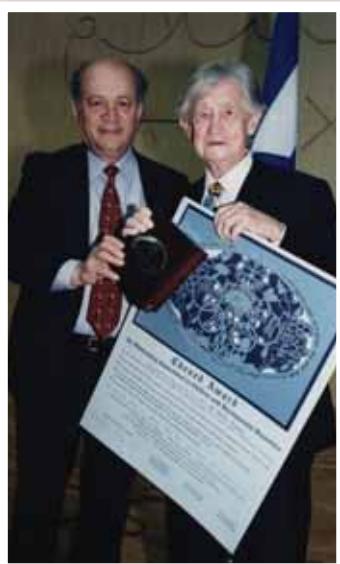
Esther & Sydney Boyd with their children Ronit & Michael and Eitan & Dara





Willie & Celia Trump
at the 1983 dedication
of the Trump Social
Activities Center

The influence and contributions of the family of the late Celia and Willie Trump can be felt throughout the organization. Notably, they have taken a great interest in the training of professionals and in 1996, the Trump International Institute of Developmental Disabilities was set up in their memory.



In 1999, Willie Trump received the First Chesed Award, for his lifetime contribution to people with developmental disabilities. The event was held at the Knesset and the award made by then Minister of Health Yehoshua Matza. Subsequently, the Trump family endowed an annual award for excellent service in the field of disabilities. This was just one of their efforts to reward dedication and motivate higher service standards.





BIS opened in 1981, in a house in Herzliya



Some of the first children and their caregivers



It was an exciting occasion when Mrs. George Schultz together with Mrs. Alice Pickering, wife of the US Ambassador, honored BIS with a visit.



The new Beit Issie Shapiro Center was officially opened in 1987, in Raanana



The Raanana Municipality, recognizing the Center's growing importance to the community, named the approach road "Issie Shapiro Street"!



In early years, everyone's "Uncle" Willie Trump, with Jean Judes, who has since become Executive Director, and Lili Levinton, who started as a psychologist and today is Deputy Director of BIS.

In 1981 BIS opened its first Special Education Center in Herzliya. In 1987, the Leon and Ben Jacobson Special Education Center was dedicated in Raanana and when this Center was expanded and upgraded in 2002, the Reuven Breinen Estate endowed the new building.



The late Joseph Lipski of the Reuven Breinen Estate, at cornerstone laying ceremony of the new Special Education Center



Unveiling of the Leon and Ben Jacobson Special Education Center

The Center developed a wide range of innovative educational methods to enhance the functioning of children with moderate to severe intellectual disabilities. It is recognized by the Education Ministry as a model center.



In 1982 BIS, in partnership with Helene and Jack De Lowe, opened the Aaron De Lowe Early Intervention Center, the first for young children with developmental delays. The Rehabilitative Day-Care Centers Law (2000) entitled every infant with special needs over one year of age, to receive therapeutic intervention. Today BIS's model is used as the standard setter for developing services throughout the country.



Opening of the Aaron De Lowe Early Intervention Center in 1982. Jack, Helene and their children, Troy, Susie and Lana with photograph of the late Aaron.



The Winnick Family Foundation lobby



From the outset, BIS has been concerned with supporting and empowering the parents and extended families, and In 1981, the first psychological services for the families were opened.

Today, family education and support are integral to all therapeutic and educational programs and a wide range of services are available. Parents are also encouraged to participate on committees and play an active role in advocating on behalf of their children.

In 1999, BIS opened its Family Therapy Center.

BIS's contribution to the development of family services is regarded by the authorities as a model approach and BIS has been invited to partner with other organizations in developing services in different parts of the country.

Nir Brunstein of the fundraising committee with his daughter Tal



In 2007, the Lubner Family Therapy Center was dedicated by Hilary and Bertie Lubner, seen here with their son, Marc.



Team with Director Bonnie Amrami



BIS board member Tal Eisner with Miki and their son Rani

In 2009 a breakthrough was made in opening the first "Dual Diagnosis" program for people with both developmental disabilities and emotional and psychological problems.

Now for the first time a community - based program would begin to study the interplay of these issues and develop new treatment models.



The opening of an Ambulatory Treatment Unit in 1983, brought children with minor developmental difficulties to BIS and created a normative atmosphere. This gradually reduced prejudices and the social isolation of those with disabilities.

The Unit also developed collaborations with the medical insurance funds, and fought for the rights of children with special needs to receive ambulatory treatment.



Mona Julius,
Manager of Ambulatory
Treatment Unit



Physical therapy



Music therapy



UK Board members
Alex and Aidee Beare
next to the room they
dedicated to their
mother, Marika Beare



Speech Therapy





Early on the organization recognized the importance of enriching the skills of professionals giving service to people with developmental disabilities. Seen here is the 1st Issie Shapiro Memorial Conference, held in 1983. Subsequently BIS has hosted five international conferences.

The establishment of the David Beare Training Center in 1985, was a further step towards providing specialized training in this field. This led to a collaboration with the Bob Shapell School of Social Work at Tel Aviv University. Later programs were established in diverse disciplines at various academic institutions.

Today the center provides field training for over 85 students each year from academic institutions from around the country.



Children of the late David Beare:
Gillian, David,
Steve & Danielle Martin





Until the 1980's only a narrow range of dental interventions were available to people with developmental disabilities.

In 1989, with the encouragement and support of South African dentists, Dr. Brian Braude and Dr. Trevor Segal, and the contribution of Gan Oranim and Naomi Ditkovsky, the Shimon Ditkovsky Clinic was established. This became the first community-based clinic to serve exclusively people with developmental disabilities.

Dr. Udi Yoge who directed the center until 2011



Today the Clinic provides a full range of interventions including anesthesia, orthodontics and implantations. It also operates screening programs throughout the country and gives educational workshops to expose dental hygienists and practitioners to treating people with disabilities. Through these pioneering efforts, BIS has put a smile on the faces of thousands of children and adults with disabilities.

The late Dr. Brian Braude, partner in pioneering community-based dentistry for people with developmental disabilities in Israel



Senior academics from Tel-Aviv University's Goldschleger School of Dentistry were partners in the development of the Shimon Dental Clinic

When Naomi Ditkovsky passed away in 2005, the Clinic was renamed the Shimon and Naomi Ditkovsky Dental Clinic



It was through a partnership with the South Florida community, that money was raised to build the Williams Island Therapeutic Swimming and Recreation Center, which opened in 1992.

Under the direction of Tuvia Stuchiner, hydrotherapy became a recognized treatment method and an intrinsic element of the treatment for a wide range of ailments and special needs.

BIS established a reputation for training hydrotherapists, developing specifications for the building of therapeutic pools and for research. The Center is now under the direction of Ilanit Weigenfeld-Lahav.



Watsu training



Tuvia Stuchiner, pioneer of hydrotherapy in Israel



Above is a photo of Trump family at the opening of the Center, with the late Jaapi Kroonenberg (inset), a major contributor.



The center also offers competitive swimming programs for people with disabilities.

Here Tamar Pugatsch proudly receives an award.

Among the innovations of the Williams Island Center, are:

- Infant hydrotherapy
- Watsu treatment
- A “Snoezel” swimming pool
- Competitive swimming



In 1993, with funding provided by the Wolfson Family Charitable Trust, BIS pioneered the establishment of the first Snoezelen, controlled multi-sensory room, in Israel.

This led to a new treatment emphasizing the impact of the sensory environment on people with special needs.

The program was developed from its inception by Dr. Michele Shapiro, seen below, who has become a world authority on the method. A boost to its impact was given by the Lorraine White Foundation which has, for many years, subsidized the cost of training in this method. Today Snoezelen rooms have been built in diverse settings throughout the country.

Backed by a body of research, controlled multi-sensory intervention has had a great impact not only on treatment, but on the design of therapeutic milieu, and Dr. Shapiro is consulted in many parts of the world.



Harvey Kaylie & family, of the Lorraine White Foundation unveiling the plaque



The new Dark Room was inaugurated in memory of Bunny Levey, by Gail and Judah Schorr

Dr. Michele Shapiro



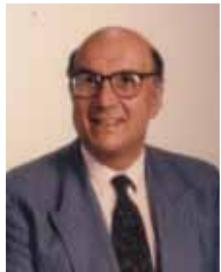
First 'Snoezeled' hydrotherapy pool



First 'Snoezeled' Dental Clinic in the world!



The Jonah Press Sports Center



The late Torsten Press



Dedication of the Torsten Press Challenge Room with family

The Jonah Press Sports Center is directed by Nira Stern (far right)



The late Jonah Press



When Lolou and Torsten Press asked their young son, Jonah which was the best day of his life, he told them it had been a day of sport and fun. After his passing, they established the Jonah Press Sport Therapy Center at BIS, in 2000. Today most of the children at BIS do regular work-outs and the Center offers programs to the community.





The Sindian Center held its first annual fundraiser in 2007



The Trump International Institute provided training for the first Arab professionals working in Early Intervention, including speech, physical and occupational therapists, psychologists and social workers.

In 2001, partnered by the Helen Bader Foundation, Inc. BIS opened the first Early Intervention Center for Arab children, in Kalansua. The center was subsequently named the Sindian Early Intervention Center.

Over the past 10 years, this Center has become an integral part of the Arab community, providing treatment and education for children, a range of family support and empowerment services and opportunities for community involvement.



Today the Center is funded mainly by the government of Israel and the local Arab community, and is staffed by professionals from the Arab community. Beit Issie Shapiro provides training, guidance and support.



1996 also saw the development of social and educational inclusion programs for young children with moderate to severe intellectual disabilities.



Ori Schreiber, as an infant in the Aaron De Lowe Center, singing with Dedi Graucher and the Army Rabinical choir, and then proudly as our first soldier, in 2010



Children in inclusion program



Edna Karni, who developed the inclusion program in the Early Intervention Center



BIS community intervention team works to ensure that the rights of people with special needs are respected and that they are able to access appropriate educational, health and social services. They develop partnerships with other agencies in order to influence policy and legislation and advance the integration of people with developmental disabilities in the wider community. The program, which is directed by Shosh Kaminsky, includes:

- Accessible - inclusive adventure playgrounds
- Youth leadership and tolerance program
- Social Advocacy programs
- A Social club for people with intellectual disabilities
- Volunteerism
- Family support programs
- Consultation on community service development for people with special needs.



Shosh Kaminsky directs the Community Programs



Annual volunteer conference

In 1997 BIS developed Project Chen, which reaches out to 30 schools around the country each year, impacting on hundreds of youth, identifying and encouraging them to become socially active leaders working towards a socially responsible and inclusive society. The program is managed by Ronen Cohen.

Shown here are groups from Milken High, LA and Reuben Gitelman school in Rockland County, NY, that participated in Youth Twinning Programs with Chen.



Adult Social Club



The Chen Project has been adapted to include youth with and without disabilities and groups of youth at risk.



Ensuring that children with special needs are included and have access to public facilities has always been a high priority at BIS. In 2006 a social breakthrough was made, when the municipality provided land in the central park of Raanana, to erect a fully accessible and integrated park. The JNF, UK equipped the park, which was named: Park Chaverim - Friendship Park.

Park Chaverim was unique in Israel and the first park where children with special needs could enjoy facilities alongside regular children. Children from across the country were brought to the park for social programs and had the opportunity to play with children with special needs, learn about disability, and how they could play together with respect and caring.



It was a great occasion when “Sesame Street” came to Park Chaverim highlighted the value of befriending children of all abilities and giving a hand to those who need a little extra consideration.

Since then many municipalities have emulated Park Chaverim, leading to a radical change in the way recreational facilities are conceptualized in Israel. Today most developers ensure that their facilities can be enjoyed by children with diverse abilities.



The carousel is situated at ground level, making it possible for a child in a wheel-chair to board and enjoy it safely.



Swings come in different shapes and sizes, with the emphasis on allowing children to swing and socialize together.



As early as 1983, Lucie Shapiro was committed to sharing the story of BIS and to recruiting volunteers to help raise money for its programs.

Lucie rallied hundreds of volunteers to pack and sell gifts. Trained by Louise Lipschitz, these volunteers are well known for their creative packaging.



From left: Lionel Samuelson, Frieda Haimowitz, Louise Lipschitz, Yaakov Buskila, Ayelet Shenhav



Ruth & Yuli Ofer

Keren Ahava sells over 400,000 gift boxes annually, to benefit BIS. The first gift shop was donated by Ruth and Yuli Ofer in honor of their granddaughter. The new gift shop, 'Lucie's' was inaugurated in 2010.



In 1995, the Annie Tollman Volunteer Center was opened. The picture shows the late Cecil Tollman, with his son, Paul.

Long time volunteer Sheila Cohen



Natanya volunteers, Cynthia Sloman, Cecil and Sheila Slome with Doron Glam





As part of its 25th Anniversary celebrations, BIS launched a Social Charter calling for the Rights of Young Children with Disabilities. Seen here: Dudu Fisher, well-known singer and actor, signs the Charter, which was co-signed by 25 community leaders in Israel and abroad.



BIS together with other organizations and partners campaigned strongly for the rights of children with special needs and in 2000, the Rehabilitative Day-Care Centers Law was passed. Today, the Act provides therapeutic daycare for all young children over a year of age. Whereas in the past, BIS was unique in providing a comprehensive service for young children, there are now 90 high quality services in different parts of the country and the Health Ministry partners the Trump International Institute, in training service providers.





BIS has always sought to involve the community in its activities and to encourage the public to have a sense of responsibility and ownership of the organization. This has been one of the motives for its strong emphasis on volunteerism. At the time of its 30th anniversary, BIS was proud to count on some 1000 active volunteers, each year.

In 1990 BIS launched the Annual Rivka Ahimeir Young Volunteer Award.



Mayor of Raanana, Nahum Hofree, with City Councillor, Bella Zur and Avi Ahimeir at the Rivka Ahimeir prize-giving ceremony

And in 2009, The Jewish Child's Day organization, in London, made a recognition award to outstanding Chen program volunteers, Yuval Laor and Noy Aviv. Here, Deputy Israeli Ambassador, Talya Lador-Fresher, congratulates the Israeli awardees.



This picture shows how the children were taken into bomb shelters in response to the frightening threat of chemical missiles during the first Gulf war (1991).

Sadly, in a country torn by terror and war, children with special needs are especially affected. Fortunately, with the help of a compassionate donor, BIS was able to invest in a filtration plant so that in the future they would be spared the trauma of having to wear gas masks. During Operation Cast Lead in (2008/9), BIS initiated a range of supportive services to families with special needs children living in areas with situations of terror and trauma.



Giving back to the community has always been an important value. In 1985, BIS innovated “Salute the IDF on Yom Ha’atzmaut Program” connecting children with disabilities to the Israeli army.

This has fostered a special relationship with the IDF. Today hundreds of soldiers volunteer to help pack gifts for sales over the Jewish festivals.



In 1994 BIS took the strategic decision to open a training institute. Today, the Trump International Institute provides hands-on training for thousands of professionals, volunteers, parents and people with disabilities.

Training is provided at BIS or at distant points in the country, as well as abroad, and the Institute is responsive to the needs of the community. The Institute undertakes training for and in partnership with government ministries and non-governmental organizations and pursues its mission of raising awareness and standards of service to people with disabilities.

In 1994, BIS hosted its first international conference and this has subsequently been hosted by the Institute on a quadrennial basis. Experts are brought from abroad to address delegates and the conference also provides a forum where local experts can share their knowledge.



Stephanie Trump opens the new home of the Trump International Institute of Developmental Disabilities, in 1996



In 2003, under the direction of Dr. Benjamin Hozmi, The Trump International Institute opened a remarkable new venture – a Special University for people with learning and social adjustment difficulties. They did so in partnership with Bar Ilan University, offering these students a unique opportunity for an enriched education at a highly respected university. The “Art of Living” and other courses are offered annually.



Students
listening to a
lecture in the
Marc Tager
Auditorium



The Trump International Institute has hosted five international conferences with participants from over 20 countries.



Bella Zur, member of Raanana council and an activist for people with disabilities

The late Dr. Lucille Strauss, national consultant for AFOBIS, established and nurtured the development of the Professional Advisory Committee in NY, which has provided scientific backing to all the conferences. Today the PAC boasts members in many parts of the world and BIS has developed a wide network of professional support.

Former MK Tamar Gozansky, Professor Arie Rimmerman and Jean Judes at the 4th International Conference



At the 1998 conference, the late Professor Stan Herr (seen above with conference chair, Dr. Pesach Gitelman) focused attention on the rights of people with disabilities. After his untimely passing, the Warriors for Disability Award, was established in his memory.



Professor Herb Cohen, past chair of the NY PAC, accepts a certificate of recognition in memory of the first chair, the late Professor Larry Taft, at the 2004 conference



In 1993, BIS took the unique step of establishing an in-house Research and Evaluation Unit. This has been directed from the inception by Dr. Dana Roth, Ph.D. Ed. Psych/Special Education. Over thirty years some 60 research articles and books have been published.

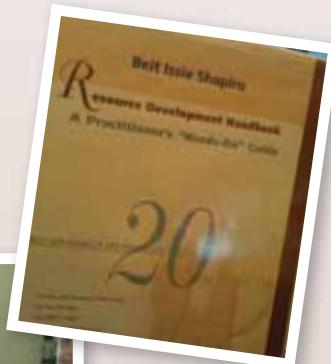
Today, research is integral to the work done at BIS. All programs are monitored and evaluated to ensure that they meet their objectives and the needs of the people they serve.

One of the most highly regarded programs is the participatory research program - in which students undertake research on matters of interest to them. Dr. Roth is seen in the center of a group of her students. This program was endowed in memory of the late Nathaniel Richman Cohen.



As well as having published many articles in academic journals, BIS has also published collections of articles and books on specialized topics.

In order to raise the funds needed for the development of programs at BIS, it was essential to implement a professional and diverse fundraising program, and this meant providing the staff with special training. In 2000, on the occasion of the 20th Anniversary, BIS published its First Fundraising Handbook, written and edited by Sharon Bacher, Naomi Stuchiner and Dr. Pitzie Lando. This became the standard in-service training manual. It was dedicated to the memory of Ruth Inbar, Hebrew writer and P/R officer for BIS until her untimely death in 1999.



International Desk Staff, 2008: Esther Boyd, Naama Gat, Andi Saitowitz, Sharon Bacher and Nikki Leviner



In order to keep in touch with friends and donors around the world, BIS invested in developing a range of informative resources including newsletters, information sheets, video clips and a website. In 1985 BIS produced its first newsletter, which it sent to its growing list of friends and donors. Today it has a mailing list of some 20,000 people in Israel and abroad, who receive regular updates about events, achievements and changes.

Until her retirement in 2010, most of the English language materials were developed by Sharon Bacher.



Over the years, BIS received several certificates of recognition and excellence. These include:

1989 Naomi Stuchiner, Beit Issie Shapiro's Executive Director until 2006, was awarded the Henrietta Szold Prize for Social Work.

1999 Beit Issie Shapiro was awarded the Prime Minister's "Shield of the Child" Award for excellence in services.

In 2000, our dental practitioner volunteers were awarded the Keren Shalem "Yakir" award for their outstanding contribution to people with developmental disabilities.

In 2002, Michele Shapiro was awarded by the Israeli Organization for Occupational Therapy for the contribution towards development of innovative service of Snoezelen in Israel and internationally.

In 2004, Naomi Stuchiner was awarded the Manager of Distinction Award for leadership and management in the non-profit and voluntary sector.

In 2007, Naomi Stuchiner was awarded a "Life Achievement Award" by the Institute of Certified Public Accountants in Israel. The award was presented in recognition of her outstanding contribution to the field of disabilities.

In 2008 Naomi Stuchiner and Dr. Michele Shapiro received the Telfed Yakir Zion Award.



In 2009 BIS was awarded the highest management rating by Midot - the Israeli non-profit charity standards bureau, which is equivalent to the USA Charity Navigator - on five critical measurements: Ethics, Finance, Systems, People, Horizons.



We honor the memory of the late Gerald Blackman, head of Audit Committee, involved since the inception of BIS, who took great care to ensure high financial standards and transparency.



Towards BIS's 20th Anniversary, in 1998, celebrations involved the whole community, with a highlight being the "Halevai 2000" party in Raanana, with children with special needs and their families, dispersing balloons carrying their wishes, into the heavens.

BIS celebrated its 10th Anniversary with a wonderful party hosted at Gan Oranim, for the children and their families



TV host, Dan Shilon and singer David Daor, at BIS Barmitzvah Celebration



Jules Trump and Tamar Pugatsch at 18th Anniversary celebrations



Former Prime Minister of Israel, Yitzhak Shamir, visited BIS's Sukkah With Mayor of Raanana, Ze'ev Bielski



Former Deputy Mayors, the late Uzi Cohen and Zvi Kenig, with then Deputy Minister of Labour and Welfare, Rabbi Menachem Porush



Raanana Council member Zvi Kenig with CEO Yossi Ravid, Mayor Binyamin Wolfowitz with Lucie Shapiro



Jerry & Eileen Lieberman
Previous Co-Chairs of the Amerian Friends of BIS



Lou Brause, former Chairman of the NY Board of Directors and family visit BIS



Vodkas and Latkes event, NY 2010

New York Board members Ruvan & Shelley Cohen; Mark & Lisa Todes; Alisa & Chairman Alvin Broome; Joshua & Lizzy Trump with AFOBIS National director, Ed Ward at Family Day event IN 2009



Josh and Lizzy Trump,
co-chairs of the Cirque
De Sol Event, 2007



Family day, NY, 2009



New York

From early days, it was clear that despite the strong backing of the Shapiro extended family, it was essential for the organization to invest in grassroots support abroad. The large extended family living in many different parts of the world, provided a launching pad for resource development in the USA, Canada, the United Kingdom and South Africa.

Today each of these centers of influence has an office run by a small staff and many dedicated volunteers. Over the years they have raised millions of dollars towards services for children and adults with special needs in Israel, have partnered the development of professional services, celebrated their family occasions with children at the center, visited and introduced their own family and friends. They have provided much of the backbone financing that has allowed BIS to become a world leader in its field.



Events in Florida to benefit BIS



With Stephanie Trump, Lennie Miller,
John Bussel and Benjy Maor



Florida Board, 2000, Joel Matus, Alan Matus, Naomi Stuchiner; consultant Steve Rose, Stephanie Trump, Nathan Lewinger and John Bussell



With Nathan & Toby Lewinger,
Andrea & Freddy Frohlich;
Jean Judes and Naomi Stuchiner



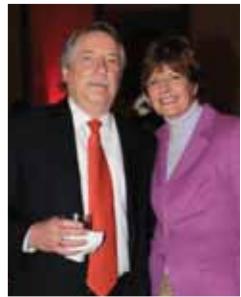
Greater Miami Federation leadership with Barbara Goldfarb, Norman Braman, Bill Lehman ; CEO Jacob Solomon and Raquel & Michael Scheck



Greater Miami Jewish Federation leadership:
Michael Scheck, Bob Werner, Norman Braman,
Norman Lipoff with Jules Trump &
Naomi Stuchiner



Sasha Weiss and Nicola Roth
(both previously Trump) Miami Friends of
BIS at Israel Day 1989



LA
co-chairs
Pat &
Errol Fine



Los Angeles

LA co-chairs
Marty & Marilyn
Spiegel

LA Gala 2010, guest
of honor Holly Pete
Robinson with Mom,
Moriya Shalev



Haim Saban and guest speaker,
Dr. Cheryl Saban at LA Gala 2008



Cycle for Smiles nursery
school teachers

London

Dianne Kutner, Paul Kutner, Lewis Bloch,
Mike Hirsch - chairman of UK Friends
of BIS, Colin Foux, Karin Hirsch, Seated
from left: Edith Hirsch, Sandy Foux



Sylvaine & Bill Zucker from New
Zealand, with Benjy Maor, Jean
Judes and Naomi Stuchiner



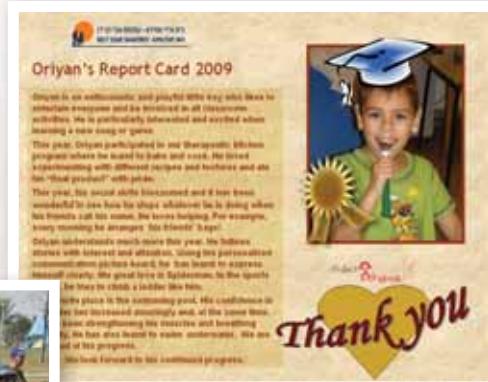
The Cycle for Smiles Campaign was initiated by Margie Ipp, director of Temple Judea nursery school in LA, as a brilliant strategy for bringing that community close to the children of BIS in Israel.

Under the leadership of Amy Slater-Ovadia, this program spread through the community. It targeted pre-school children to ride their bikes for a special toddler in Israel. By 2010 some 40 schools participated, and through them, their teachers, parents and siblings have came to identify with and contribute to BIS.

Many of the children in the Cycle for Smiles program contribute towards the children at BIS through Project Ahava, which links donors to individual children. In Israel, Andi Saitowitz makes sure that the donors are kept informed about the progress of their child.



Cycle for Smiles newsletter, telling LA friends about BIS and about the wonderful things their community was doing to help them



Marie Ipp, founder of Cycles for Smiles



Amy Slater-Ovadia,
Director of Cycle for
Smiles from 2002- 2009



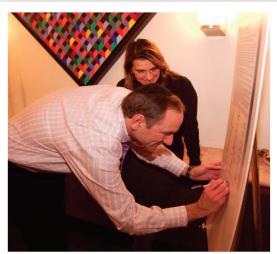
Barbara Abrams and Renee Rubinstein at event in Toronto

Toronto



Henry & Julia Koschitsky

Errol & Esther Singer, signing the Charter of the Rights of Children with Disabilities



Young Toronto leadership with Chair Gilad Epstein



Gabi Weisfeld, funding pioneer of the Special University



Canada Chair, Trevor Stein, with co-ordinator Jocelyn & Alfie Emdon

Holland



Sophia Loren, guest of honor at gala dinner in Amsterdam with the late Lucie Shapiro, and Tuvia & Naomi Stuchiner

South Africa



Brenda Solarsh, Executive Director of the Selwyn Segal Hostel in Johannesburg



The late Aaron Beare was committed to BIS from its inception and the Beare families have made a substantial investment in BIS. The Cissy Beare Administration Suite is named after their mother, while the Social Education Center is named after the late David Beare. The Aaron Beare Foundation has provided subsidies for thousands of children who have needed treatment through the years, making it possible for BIS to live up to its ideal – to provide treatment for every person who needs it, even if their parents can't pay full fees.



The late Aaron Beare



The late Aaron & Cissy Beare



The trustees of the Aaron Beare Foundation, Julian Beare, Reg Berkowitz and Bernice Beare



Derrick, son of Arlene & the late David Beare, with wife, Ariella and their children



Ambassador of China, Chen Younghou



Ambassador of Poland, Ms. Agnieszka Magdziak-Miszewska



UK Ambassador to Israel, Mr. Matthew Gould & his wife Celia



Always looking to make new friends and spread information about its work, in 2005, BIS established the Anda International Diplomatic Corps. The project was named in memory of the late Anda Zimand and is led by former Israeli diplomat to Nicaragua, Dr. Dalia Pazi. She ensures that diplomats and their wives have the opportunity to visit BIS and learn about the organization. This has also helped BIS make new professional connections abroad.



Ambassador of South Africa,
Maj. Gen. Fumanekile Gqiba and
Mrs. Vuyiswa Gqiba with Dr. Dalia Pazi
& BIS Executive Director, Jean Judes



Henri Zimand, inspiration behind
'Anda' International Diplomatic corps

Visit of Vice President of Ecuador,
Mr. Lenin Moreno



Virtual Shareholder

In 1999, BIS established its Virtual Stock Exchange, engaging the corporate world to partner with it. The return on their investment was the smiles, health and wellbeing of the children. This has become the flagship fundraising program for BIS in Israel. Each year BIS issues a prospectus outlining the successes of the social start-up in which they had invested.

Dan Gillerman, former Israeli Ambassador to the United Nations, was a guest speaker at a Virtual Share breakfast. Seen here with friends Zvi Ziv and Boris Krasny



Elliot & Debbie Tannenbaum



Dodi & Rafi Maor

Nili & Yehudi Lipman

Zvi & Jo Ziv

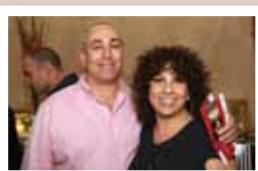
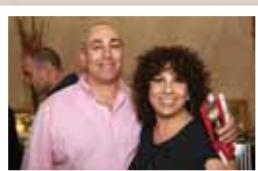


Underwriters Eyal & Susan Kishon, together with Eddy & Nili Shalev of Genesis Partners

Michelle & Tzvi Neta with Zaki & Vivien Rakib

Brigitte Kormind and Werner Bachmann

Chemi & Gila Peres



The Philanthropic Stock Exchange of Beit Issie Shapiro launches its Virtual Share offering annually.

Over 100 children from Israel and abroad, have shared their bar / bat mitzvah celebrations with children at Beit Issie Shapiro.

Towards BIS's 25th Anniversary, it launched a Bar / Bat Mitzvah Twinning program, in which children in Israel and abroad could include a child at BIS in their celebrations. To commemorate these coming-of-age events, BIS volunteers created a magnificent quilt featuring pictures and messages from the celebrants themselves. The quilt now graces the foyer in the Trump International Institute of Developmental disabilities.



Jackie Cohen, NY and David Martin, UK – first celebrants

Clayton Stone and family



Rachel, Lauren and Danielle Monk



Jonathan and Ariel Broome

Brandon Neumann and Alon



Jake Beare



Steven Greenberg

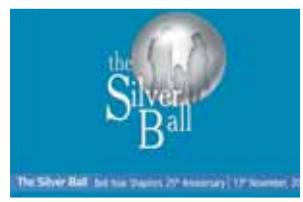


Harel Rush and family

Barmitzvah quilters: Terry Mowszowski, Rifka Bernstein, Marlyn Butchins, Monika Taizi, Ramona Buchmann, Zvia Strahilevitz-Klein and Carol Smith



When Beit Issie Shapiro turned 25 in 2005, there was good cause to celebrate its many achievements and contributions. The Jubilee celebrations included a mission from the USA and a grand Gala, with special guest of honor former President William Jefferson Clinton and dignitaries from Israel and abroad.



Above the President with Tuvia & Naomi Stuchiner, below with Shari Arison, and with Eddie Trump

October 25, 2005

Warm greetings to everyone gathered to celebrate Beit Issie Shapiro's Silver Jubilee, which commemorates 25 years of service and devotion to people with developmental disabilities in Israel and around our world. I commend your organization for raising awareness about this important issue and for sharing your knowledge and experience with colleagues across the globe.

Thanks to your commitment, the vision of Beit Issie Shapiro has become an integral part of the social fabric of Israel. Through your sensitivity for people with special needs and their families, you have made a difference in countless lives. I am deeply moved by your compassion toward people who are different, and I congratulate each and every one of you for making Beit Issie Shapiro's important mission a part of your lives.

Through the continued partnership between your organization and its supporters, I am confident that Beit Issie Shapiro will continue to serve as a symbol of excellence, bringing hope and opportunity to all Israelis with special needs.

Best wishes for a wonderful event.

Bill Clinton

Naomi Stuchiner with President Shimon Peres



Some memorable events in Israel



Radio 90 FM Telethon with Jean Judes and Board member Sima Perry



Soccer for BIS event with Bnei Hasharon



Event at the residence of the UK Ambassador to Israel Sherard Cowper-Coles



Chef's dinner with leading Israel chef, Shalom Tzadok and other international chefs



Late Nahum and Nava Sharfman at gala event at home of H.E. the Ambassador of Ecuador Mr. Francisco Riofrío Maldonado



Chinese dance company My Dream



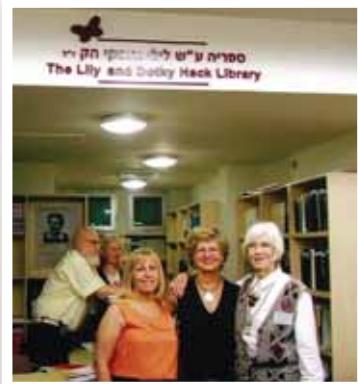
Israel Resource Development Department Manager Sigal Winter with team: Bat-Sheva Regev, Irit Jacobowitz and Noa Notsani.
Right: BIS photographer Alberto Birmaher



With BIS's enormous development from a center providing education and treatment for 16 children in 1980, to a multi-purpose organization working on a number of different levels simultaneously and serving upwards of 30,000 people each year, it became necessary to re-build, extend and re-furbish the campus in Raanana. The new campus was formally opened in 2008.



Rabbi Lau, then Chief Rabbi of Tel Aviv and Nahum Hofree, Mayor of Raanana, with Executive Director Jean Judes



Librarian Rima Watson, Dr. Louise Kessel with her Cousin Adrienne Levy



Former Minister of Social Affairs, MK Isaac (Buji) Herzog, Mayor Nahum Hofree and the Director General of the National Insurance Institute, Esther Dominissini





Participants with
Prime Minister
Ariel Sharon



Governor of the Bank of Israel, Stanley Fischer, receiving an award from Executive Director of BIS, Jean Judes



Dan Senor



Participants of
mission in 2010



A panel conducted by Dan Senor, with Chemi Peres, Tal Keinan, Meir Brand, Eddy Shalev and Scott Tobin



Some of the many people who are contributing to Beit Issie Shapiro.



Eyal Rapoport, Director of Keren Ahava



Past and present Assistants – from left:
Adela Hahamy, currently BIS Head of Human Resources,
Sharon Yeheskel-Oron & Ronit Birmaher Levari



Board Member Sasha & Yoni Weiss



Manager of logistics
Yehiel Weiss

Board member Saul & Nirit Fine



Bank Hapoalim supporters Yair Seroussi (third from left), Shelly Amir (second from left) and Yoram Weissbrem (second from right) with Jo Ziv, Sigal Winter and Jean Judes



Brenda & the late
Gerald Blackman



Irit Turel, Manager of Allied Health Services

BIS Board members Adv. Daniel Sror and previous chairman Geoff Tollman



Yehudit Amir-Gross, first staff member of BIS, who recently celebrated her 30th Anniversary at BIS

In 2006, Naomi Stuchiner formally handed over the leadership and direction of BIS, to Jean Judes, formerly the Deputy Executive Director and Professional director for 13 years. Jean Judes continues to pioneer new developments with an emphasis on knowledge development and sharing. Naomi Stuchiner remains on as its Founding President.



Long time friend and advisor Pupi Arieli of Stern Arieli Public Relations

Naomi Stuchiner with colleague, Angela Harding, who came from London for the farewell

With BIS Chair, Caron Bielski and MK Ze'ev Bielski, a long-time supporter and friend of the organization



MK Ze'ev Bielski, and MK Isaac (Buji) Herzog, former Minister of Social Affairs and Social Services

"Beit Issie's foremost legacy is one of human rights... it acts to change the quality of the lives of people with disabilities and their families."

(Professor Arie Rimmerman)

TELLED Director Sidney Shapiro



Adv. Ophir & Miri Katz



BIS Board member Zeev Abeles



IV

Resource Development

Resource Development as a Tool for Societal Mobilization

Naomi Stuchiner

My late father was the ultimate social entrepreneur and fundraiser. He died suddenly before I had a chance to learn his craft directly from him. Before then it had never occurred to me to ask. I never gave any thought to the methods he used to fundraise, or to the theoretical underpinnings of his success. He was an artist, and it seemed to me that he knew instinctively how to "turn people on". He talked, and his listeners put their hands into both pockets, taking out a checkbook from one pocket, and a handkerchief from the other. At the time, I just took for granted my father's temerity in asking people for money. I didn't imagine that one day I would be doing the same thing.

Introduction

In this chapter I will describe how BIS combined resource development with societal mobilization, leveraging its professional work with children with developmental disabilities to effect broad social change. BIS's professional approach to resource development is grounded in the intersection of three different variables: 1) the needs of a defined population (in our case: children with developmental disabilities and their families); 2) the strengths inherent in the community; 3) the needs of the organization.

First I will describe the social context in which we began - the beginning of the transition from a welfare state to the privatization of social services. Then I will briefly describe some of our ventures that combined resource development with mobilization of a specific community. And finally I will set out some of the components of the professional approach that underlay our successes in this area.

The Social Context: Transition from a Welfare Society to Privatization

BIS began to operate in a critical point in the development of welfare and health services in Israel – the initial stages of their privatization - a process that progressed rapidly over the years to come. Prior to privatization the State of Israel operated as a welfare society in which the government was almost exclusively responsible for solving social problems. The large and traditional service organizations were funded primarily by the government, and often included an additional source of funding coming from door to door solicitation by children from schools or youth movements.

The establishment of a not-for-profit organization in Israeli society of the 1980's was challenging. The Not-for profit Organization Law became operative in 1980 and Beit Issie Shapiro was registered as "Amutat Avi". Recognition as a not-for-profit allowed us to raise money and later to be recognized for that purpose by the income tax authorities. But entry of a new family-run non-profit organization into the welfare domain was accompanied by skepticism, sometimes with derision, and certainly with very little cooperation. Indeed it was made very clear to us, that we had almost no chance to last beyond our first year.

Like our late father, we believed that with determination, persistence and belief in the justice of our cause, we would succeed in changing attitudes and perceptions, not only with regard to the right of people with disabilities to be in the community and to receive appropriate treatment there, but also with regard to the roles and responsibilities of citizens of Israel. Over the course of time, these new perceptions became the value base for the development of the third sector and of modern-day philanthropy in Israel.

In those days the allocation of government funding for services for children with special needs was very low, which meant that the standard of services was inadequate. It was clear that if we wanted to raise standards we would have to secure independent funding sources. The recognized mode of giving in Israel at the time was ad-hoc contributions, such as to the Israel Defense Forces in times of emergency, or to other well-known national organizations. There was little chance for a small, new, localized organization, to have access to serious fundraising opportunities. It was clear that in order to generate interest in and support for a new organization, especially for a cause that people preferred to avoid, the welfare of people with intellectual disabilities, we would have to break down stereotypes and change people's attitudes. We had a double goal: building the best treatment programs which would meet exemplary standards, and mobilizing the resources to finance

them. We knew that here in Israel we would need to begin by casting a broad net of solicitations that would begin with small donors.

The Challenge of Gaining Visibility

From the outset, one of the challenges for Beit Issie Shapiro was becoming known to the larger community in Israel. We faced two obstacles in our efforts to create a broad awareness of our activities and mission. First of all, as we were a family-initiated non-profit, people outside of the family had no particular reason to identify with us or with our cause. Secondly, as we were operating in an area of society (developmental disabilities) that evoked stigma and even fear in the general community, there was a great deal of reluctance to talk openly about what we were doing and whom we were serving.

The issue of family was discussed at length in chapter 10. Our central strategy in dealing with this first obstacle was to expand our notion of ownership to all other interested persons, including them in the wider, extended "family". We invited the entire community to become full partners in everything we did and over time we broadened our support base.

The issue of stigma, discussed in chapters 1 and 3, was particularly challenging. The families themselves felt shame vis a vis the general community and were reluctant to speak publicly in a way that they could be identified. This was a serious obstacle to getting any coverage in the media, since the media is always most interested in personal stories.

Determined to change attitudes about people with disabilities, to bring home our conviction that these are regular people who deserve to be included in the community, we reached out to the public. This was not always well received – we were criticized for spending money on PR, for ‘using’ our children to get attention and generally for making the issue of developmental disability more public. But we stuck to our guns, knowing that the only way people with disabilities would be recognized and given equal opportunities, was if they gained exposure and attention.

It took several years of public relations and community education, alongside proving over time that we were worthy of our parents' trust, for parents to begin to step forward and to share their experiences openly. Once they did so they became our foremost advocates for change in the public's perceptions of them and their children. One of our biggest coups in this regard was bringing a number of young celebrities to Beit Issie. Their meetings with the children and parents led them to

choose to identify themselves with our cause and to feel good about becoming our champions. Their contribution to promoting the values of inclusion in Israel was invaluable.

Our conviction paid off and as time went by, it became acceptable procedure for non-profits to use professional public relations in order to tell the organization's story. Moreover, it became clear that public relations was an essential tool to support fundraising. In 2010 we undertook a survey to evaluate the degree of public awareness throughout the country of the organization. It turned out that 63% of the Israeli public had heard of Beit Issie Shapiro, testifying to the success of our multi-faceted efforts to raise awareness.

Campaigns that Combined Resource Development with Community Mobilization

From our earliest day we acted to engage all of the interacting circles of interest and influence involved with our organization. At first there were contributions from the family abroad. When we looked for resources in our local community, we immediately identified the English speaking community, immigrants who had been raised with a sense of responsibility for taking an active role in their communities and who were eager to get involved and contribute in Israel. Since we belonged to this community, the connection was relatively easy, and we began there. We were fortunate that many of these immigrants became the core of our volunteers in Israel and even helped us make connections with potential donors in their countries of origin.

From Gift Packages to Keren Ahava

The Selwyn Segal Hostel, the residential facility in Johannesburg for people with intellectual and other disabilities founded by my father among others, had long operated a highly successful project of selling gifts for the holidays to members of the community. The entire Jewish community (then as today) used to buy their gifts there, happy to be doing a 'double mitzvah' by contributing to a worthy cause at the same time as they were giving a gift. So we too decided to begin selling gift packages for the holidays. This seemed to be a good way to combine fundraising with spreading awareness of our services and changing attitudes towards people with disabilities. We believed that as more and more people become involved, they would develop a sense of ownership and responsibility for the organization.

My mother, the late Lucie Shapiro, launched the first gift package project from her home, with volunteers who came to be known as "Lucie's Ladies". These were essentially senior citizens whose families had come to live in Israel and who found Beit Issie Shapiro to be an excellent opportunity to make a contribution in Israel, very similar to what they had done back at home. Mom, accompanied by the volunteers she enlisted from our local community, became a pivotal institution in BIS during its first two decades. The BIS gift shop is now called "Lucie's", and the annual seminar of volunteers in BIS is also named in her memory.

At first we set out paper plates on her dining room table, added a few snacks and cellophane and went out to the street to sell our gift packages. We began with 300 and when we reached 3,000 we began packaging them at my house and my neighbor's house, recruiting the help of volunteers from the youth movements and neighborhood. Each package included a page telling the story of BIS.

When we reached the 10,000 gift package sales mark, we rented a small building and recruited even more volunteers. Our project grew into an industry! We sold the packages in the schools and kindergartens, where many of the teachers used the opportunity to tell their children about the special children in the community. We also began to work with companies – they appreciated the way that we combined a donation with a wonderful gift for their workers' children for Hanukah and Purim. Our gift packages also reached the army bases thanks to Doron Raif¹, then CEO of the computer department of "Mivtachim", a workers insurance company, who took upon himself to promote our gift packages to the workers' unions in hundreds of companies in Israel. Doron also used his computer skills expertise to help us set up our first donor database.

The project that had begun so modestly is today a business subsidiary, "Keren Ahava", with sales of over 300,000 gift packages a year, packed by thousands of volunteers. The Keren Ahava Shop was set up through the generosity of Yuli and Rutie Ofer (Keren is Rutie's granddaughter), and they generously funded the first gift store at Beit Issie Shapiro. These sales afford BIS an entry into thousands of homes. In recent years the company has become very profitable and has enabled BIS to develop positive relations with companies throughout the country.

The whole area of profit-making projects has now become part of the non-profit world. More and more organizations are developing business enterprises in order to increase their income. At the time when Beit Issie Shapiro started this project, we were advised to register a subsidiary so that we would not be seen to be competing

1. As this book goes to print, we mourn the sudden passing of Doron Raif who made an enormous contribution to Beit Issie Shapiro.

with businesses and having an unfair edge over them. The regulators today recognize these businesses in the non-profit field as being legitimate and no longer penalize their for-profit activities. In fact, social enterprise is now becoming a well-accepted part of the philanthropic world and there are major discussions on this new ‘4th sector’².

From Bazaar to the Accessible Park

Another means for spreading the word and gaining community support in our early years was our annual bazaars. When we were still in our first location in Herzliya, we held bazaars both in the center of Ra'anana and in the Ra'anana absorption center. When we moved to our new location in 1987, our large parking ground became the venue for our annual bazaar and funfair for children at our center, bringing thousands from the Ra'anana and surrounding communities to participate. This became an event of major significance in raising awareness of BIS. No less importantly, it became a place where parents of our children with special needs could mingle with the community in a normative activity. Twenty years later, Park Chaverim was created to further reach that very same goal.

Gaining Exposure in the Corporate World

Our outreach to the corporate world began with a unique and creative campaign called the Virtual Shares campaign. The idea was to create a “philanthropic stock exchange” and attract corporations to buy ‘virtual shares’ in the organization. The Virtual Shares campaign was launched in 1999 when our first Mission from the United States – “the Mission of a Lifetime” - led by Jules and Stephanie Trump and Norman and Irma Braman, leading figures in the business and philanthropy worlds in the United States - came to Israel.

The event was held at the Dan Accadia Hotel in Herzliya, and Israeli actress Mili Avital from LA hosted the evening. The guests were given a prospectus outlining that there were no ‘risk factors’ in their investment, and the ‘dividends’ which could be shared by all shareholders, was their knowledge that the special children would benefit. We recruited as ‘underwriters’ the Genesis Partners company headed by Eddy Shalev and Eyal Kishon, and each shareholder received a share certificate. Zeev Abeles, chairman of the board of the Igud Bank, agreed to serve as chairman of the board of our unique Philanthropic Stock Exchange. The project was a resounding

2. Sabeti, H. with the Fourth Sector Network Concept Working Group (2009). The Emerging Fourth Sector: A New Sector of Organizations at the Intersection of the Public, Private and Social Sector", Aspen Institute, Washington D.C.

success. This became the forerunner of 11 more virtual share offerings encouraging corporations to become part of the Beit Issie Shapiro giving family.

Our corporate fundraising was taken to the next level in 2006 when Josephine (Jo) Ziv, wife of the then CEO of Bank Hapoalim Zvi Ziv, took the chair of the Israel fundraising committee. Josephine, together with Sigal Winter who has led the Israel Fundraising department since 2006, has skillfully mobilized many others in the upper economic echelons of Israeli society to join her in developing corporate giving and philanthropy for Beit Issie Shapiro. Jo formed a very active and dedicated fundraising committee with the participation of some caring volunteers, and these work together to ensure that there is a steady flow of funding to Beit Issie Shapiro. As a result Beit Issie has gained increasing visibility in the corporate world, with many businesses and philanthropists putting us on their giving list.

Special Events

Like many other organizations, Beit Issie Shapiro holds special events as a tool for fundraising. There are many opinions about the validity of these events, whether related their costs or their effectiveness.

In accordance with our "circles" approach to the community, we became increasingly aware of the need to hold different levels of events targeting different groups of people. In parallel we were always on the lookout for ideas for events that would not only bring in large donations, but were not too costly or extravagant. The high level and good taste of the events together with their emotional significance brought our donors back every year.

One of our biggest successes was the participation of former American President Bill Clinton as an honored guest in our 25th anniversary celebrations and annual Virtual Shares campaign. This turned out to be a real coup for Beit Issie Shapiro. In planning our 25th anniversary celebrations, one of our dedicated supporters suggested we go for a very top celebrity. We were indeed extremely lucky to get the connection to President Clinton, who graciously agreed to attend our special event during his visit to Israel to mark the 10th anniversary of the assassination of Prime Minister Rabin. Working with the President's team was no easy feat, and it was touch and go finalizing the date and venue for our event. Six weeks before the event itself, we finally got the approval and were able to go ahead with our plans. This event turned out to be an amazing opportunity to attract new donors and to present Beit Issie Shapiro as a world-class organization. It was attended by our virtual shareholders, joined by ambassadors from 50 countries. For all of those involved it was a once-in-a-lifetime opportunity. What was especially meaningful

was that President Clinton, who had been briefed about Beit Issie Shapiro, spoke most eloquently about the rights of people with disabilities to equal opportunities and inspired us all. We were most fortunate in having him share our message.

Part of our strategy for involving the community was to make sure we had good reasons to celebrate. In 2000, we hosted an amazing event, together with Variety, called Hallevai 2000. This was our first major outdoor concert in the park. When the guests arrived, each one was given a balloon (sponsored by one of the companies in our city), with a note attached. They were invited to write their wish for the new millennium on the note. 3000 of these balloons were released into the skies. Earlier that morning, our special children also celebrated by launching their own balloons carrying their wishes for the new year.

Another major event during our 25th anniversary celebrations took place in the amphitheater at the Ra'anana Park as a social happening to which the entire public was invited as our guests in recognition of their support through the years. About 7000 people took part in the event, together with Beit Issie Shapiro's children and their families. Artists with special needs performed alongside other top-class artists who donated their appearances. For us, it was always part of our belief that we should know how to give back to our community and not just to ask for their support.

The Anda Diplomatic Corps

In 2004 we had a wonderful opportunity through a new volunteer, Dr. Dalia Pazi - former Israeli ambassador to Nicaragua - to be introduced to the diplomatic world. This was the forerunner of one of our special strategies for resource development. With Dalia's help we were able to invite the wives of Ambassadors from many countries to visit Beit Issie Shapiro. The idea was to get their interest, to change the image of Israel by showing the best of social service delivery to the Jewish and Arab population, to engage ex-patriots living in Israel to become involved in our programs, and to investigate possible professional and funding opportunities with their countries.

In 2005 we launched "the Anda Diplomatic Corps" in memory of the late Anda Zimand, and began engaging diplomats. Many have subsequently hosted fundraising events in their homes, and we invite each new Ambassador to Israel to visit Beit Issie Shapiro when they start their tenure in Israel. Having the involvement of the diplomatic world opened up new opportunities for collaborations and friendships between our countries.

Developing Professionalism in Resource Development

In the next section of this chapter, I will present some of the cornerstones of the resource development approach that characterized BIS throughout the years.

Development of lay leadership

A major tenet for success in the nonprofit sector is that an organization is strengthened when volunteers are actively involved. The role of a professional fundraiser includes building an increasingly committed, enthusiastic and capable group of volunteers who affect the fundraising process without compensation. It was thus clear to me from early on that I needed to build a strategy for the lay leadership that would move them towards their taking over the organization's fundraising planning and implementation. In 1995 a fundraising executive committee was set up, mostly with English-speakers, each of whom was responsible for a different project. Over the years the members of the committee have been involved and empowered to take decisions. Our aim has been to facilitate their developing a shared sense of ownership for the organization. The chairperson was Caron Bielski, who later became the chairperson of the board of BIS. Later, this committee was further developed by Jo Ziv who has successfully expanded this committee to lead to new creative fundraising efforts.

The "Circles of Connections" Approach

BIS used the "Circles" approach in all our fundraising. We mapped every circle of connections – beginning with parents, through the staff, members of our community, the service establishment, donors, and the general public. In this way we succeeded in developing a very broad network of friends, each of whom became committed from a different angle, spreading word of our activity far beyond our local community. In addition we believed that the more people knew about us and had a way to express their support, the stronger the organization would become and the better would be the services that we could provide to our children.

Database

It has been our experience that the success of an organization depends upon the size and efficiency of its database, and over 20 years ago BIS began working on its first database for fundraising. This has not been an easy task – we started off by creating our own database based on one that we used in the United States, but soon discovered that there was a language problem as many of our donors in Israel were English speaking. Fundraising databases are also available, usually at a very costly price, but we have not yet mastered having one consolidated database for our Israel and global

use. My personal philosophy about databases was that there are only two profiles on the data base – one was “donors” and the other was ‘not-yet-donors’. Our goal was to ensure that each person who made contact with our organization would be included in the data base, providing a wide constituency of possible contributors and supporters. Our database has enabled us to develop an expansive network of donors and to reach them through direct mailing campaigns, newsletters, and invitations to special events or to become involved in special campaigns. This is an ongoing process and involves the cooperation of each staff person in the organization.

Supplementary Materials

As a supplement to the database we have developed high quality written and audio-visual materials that tell our story in fascinating ways. With the help of these materials we are able to share our social mission with potential donors, connecting them to the amazing work being done, and inviting them to become a part of the organization. This too is an on-going process requiring regular updated materials, used simultaneously to feed our website and other electronic media. I believe that each organization should have competent writers who are able to tell the story in the most creative and saleable way, with the skills to ‘package’ the message according to the requirements of the donor or the foundations to whom we are writing.

Writing Grant Proposals

Establishing the grant-writing unit was an important aspect of the Israel fundraising department. It became clear to us that we needed to master the art of writing these proposals in order to obtain funding from the government and from Israeli and foreign foundations. This task became an extremely important part of the fundraising task, and often we integrated the supplementary materials that we produced. In the past it was difficult to find foundations that gave grants to non-profits in Israel. With the new transparency for funding sources in Israel, this information is more easily accessible and today there are many workshops and training programs for grant-writing.

Professional Training in Resource Development

In 1998 I held the first professional training program in fundraising for 20 members of staff and volunteers. Sharon Bacher wrote the handbook together with me and Dr. Pitzie Lando, a well-known fundraising consultant who was involved in BIS during some of its developmental years. Over the years fundraising had become increasingly

professionalized and many organizations, including universities, developed training programs. In 2011, the Israeli Association for Professional Fundraising was established once again, after having been dormant for many years. This is a step that will doubtlessly lead to higher standards, and will enable organizations to be taught effective fundraising strategies by trained professionals. Throughout those years I was involved in many fundraising workshops for a broad range of professionals and laymen. Since the model we developed was successful at BIS, we began to share our knowledge and experience with other organizations who were trying to develop their own strategies.

Matching projects with donors

Over the years we learned how to relate to our donors, large and small, how to engage them, encourage them and activate them to feel really good about their giving. This was enhanced by creative programs through which we sought to match donors with projects that inspired them. This included giving the donors a sense of responsibility for the successful and continued support of their program, thereby enabling us to get long-term commitments for each endeavor. This matching process was at the heart of my fundraising solicitation in Israel and abroad and required the ongoing creation of funding opportunities for many different levels of giving. Once the donor connected to a project and felt responsibility towards it, he would often take on a shared sense of ownership and commitment to the project. This in turn would encourage him to increase his contributions to fund further development. This bonded him both to the project and to the organization.

Creating Synergy between Departments

BIS had two different resource development departments working in parallel – the Israel fundraising department including volunteer coordinators, and the overseas fundraising department (see chapter 8). These departments interfaced frequently with the public relations department, with Keren Ahava – our gift enterprise (see above), and with our financial management. As these interfaces became more complex it became clear that we needed to develop a synergy between all these departments that would lead to maximum visibility and leverage. Another critical factor at around the time that I retired from my role as executive director was my realization that in order for us to succeed in the long run I needed to delegate increasing degrees of responsibility for resource development to others in the organization.

In 2001 Sigal Winter joined the Israel fundraising staff, and since then I have worked with her intensively both as a manager and a mentor. Three years ago she took over the management of Israel Resource Development, and our connection and

my tremendous faith in her made it easy for me to hand this critical function over to her capable hands. Sigal has taken what she learned and fused it with her own personality and vision to move ahead in a number of exciting directions. She has developed lay leadership, engaging Jo Ziv and the volunteer fundraising committee to become deeply involved; made great strides in mobilizing the corporate world and Israel's economic elite to take BIS on as one of their causes; moved into new fundraising strategies such as radio telethons and direct giving at supermarkets and other chain stores. And she has carried on BIS's tradition for holding extraordinary and creative special events.

Thanks to Sigal's leadership, our staff in the diverse organizational units has learned to bridge their differences in perspective in order to work together for the benefit of the organization.

Ethics in Fundraising

The success of non-profits, particularly those who are as dependent upon private donations as we are, depends upon public trust. Donor trust is of paramount importance, and to earn and retain that trust our activities must be beyond reproach. Nowhere is ethical behavior more essential, or its absence more damaging, than in philanthropic fundraising. If donors ever feel that their money is not being used in the most efficient and ethical manner possible, that trust will be eroded. To be ethical, philanthropic fundraising must free of improper motives, unmerited rewards or personal gain³.

One of the critical issues raised in the field of professional fundraising is the problematic nature of an all-too-common practice in the non-profit world: hiring fundraisers on a commission basis, in which fund-raisers' compensation is based on a percentage of the amount of money raised. While this saves the organization of the expense of hiring salaried fundraising staff, it creates serious ethical problems.

Since fundraising is a continuing practice in which current funds received may be the result of efforts of others in previous years - just as current fundraising activities may result in funds being generated at some time in the future – rewarding only the person who completes the transaction is unfair. Secondly, donors' trust and attitudes can be unalterably damaged in reaction to undue pressure and when they realize that a commission from their gift will be paid to a fundraiser. For these reasons, throughout BIS's existence we have insisted, in our work in Israel and throughout the world, that fundraising be done exclusively on a salaried or volunteer basis.

3. Sczudlo W. (2003). Motivation: Mission or Money? from: http://www.afpnet.org/files/ContentDocuments/AP_Sept_Oct_2003_Ethics.pdf

Recognition for fundraising excellence

During the many years of our involvement, Beit Issie Shapiro became recognized as an organization with very high standards, not only in professional service delivery, but also in the public relations and fundraising world. Two years ago, Beit Issie Shapiro was awarded the highest rating by Midot, an independent organization evaluating the standard of service by non-profits in Israel. Having this stamp of approval was an important leverage for us to approach the community for larger donations assuring them that we were worthy to receive their support. We have been asked to present our model at many conferences, and once again, have used this opportunity to promote the rights of children with disabilities to high quality education, treatments and other resources. This has in turn led to more visibility and more donor support.

Conclusion

Today we are proud to say that more than half our funding is provided by donors. And we are proud that our monies raised in Israel are equal to that raised abroad.

Our motto – Obstacles are what you see when you take your eyes off the goal – is reinforced each day. Only through determination and continued focus on one's mission can one succeed.

This has been an amazing journey, helping to get thousands of people committed and willing to give of themselves and their funds. Philanthropy in Israel is changing, and Beit Issie Shapiro holds a place of pride in the change.

The Global Network and International Strategy for Resource Development

Naomi Stuchiner

Introduction

This chapter documents the history of Beit Issie Shapiro's overseas fundraising efforts, and the practical knowledge derived from this experience. In so doing, I will highlight some of the management and professional challenges faced by an Israeli organization which seeks to mobilize support for its activities abroad, and present some of the critical strategies that led to Beit Issie Shapiro's success.

However, before I begin this analysis, I want to share a few personal words. Writing this chapter has been a very moving experience for me. Now that I have handed my "baby" over to the competent hands of people, in whom I have the utmost trust and belief, I am writing - for the first time - about my work overseas.

For thirty years I have lived in two different and yet most complementary worlds. During the many years that I traveled for Beit Issie Shapiro, I always felt that while I was leaving my family at home, I was rejoining my larger family overseas. I have developed friendships with many hundreds of wonderful caring and committed people throughout the world, and this is a privilege that I do not take for granted. The love and respect that I have shared with so many have enriched my life immensely.

This chapter is dedicated to all our wonderful donors, and most importantly friends, who have made our mission possible. It was not possible to name each one of you personally, but this is a personal tribute to each one of you. In addition, I would like to salute and thank our overseas fundraising teams, in Israel and abroad, who have been full partners in this process. It has been a pleasure to work with them.

Getting Started

During his lifetime in South Africa, my late father Issie Shapiro, his memory be blessed, gathered an incredible number of supporters and admirers, both within the family and in the wider community. He passed away in the United States while on a mission to interest new people in his dream – setting up a program in Israel for people with intellectual disabilities similar to the one he had developed in South Africa. To this end, in the two weeks prior to his passing away on the flight from New York to Los Angeles, he met with a number of people and told them about his dream.

Thus when we, the immediate family, decided to carry on with his mission, it was natural to look for support abroad. We are fortunate to have a very large and wonderful extended family in various parts of the world. My late father was considered to be a patriarch and very integral part of the family, and being able to commemorate his lifetime work through Beit Issie Shapiro became a joint endeavor and commitment for the entire family worldwide.

When raising money one needs to start with one's first circle of influence – those most connected to oneself (or, in this case, to Issie Shapiro) or to one's cause. In this case, these were the people who had met my father and been inspired by his devotion to people with special needs. These family members and admirers became our first port of call in looking for overseas funding.

We knew that the pain and shock of the sudden loss of a loved one, soon fades for the broader community. Therefore we understood that our approach to my late father's family and friends would be most effective during the period soon after his passing.

Our first stop was South Africa, where we managed to garner the support of many friends and family - most of whom have remained supportive, even 31 years after his death.

Since we had close family members in the US, who were committed to supporting the program we set up in our father's memory, the US was our next stop, and it became my major region for fundraising over the 30 years that followed. I owe the development of the US fundraising to the Trump family. First of all, to my late Uncle Willie Trump and his wife, my father's late sister, Celia, who made BIS their personal mission and life work. After their death, their children and grandchildren took this project as their personal mission and commitment.

I remember how in the early days of our global outreach, I would travel to New

York with a video clip to help me tell my story. I would hire a video player in New York and carry it in a cab to potential donors introduced to me by my cousins, the Trumps. Naturally I would also make sure to have a TV screen available so I could show them the clip.

As I developed relationships with new donors, I asked them to introduce BIS to their friends and to help spread our message to others.

I soon learned that the overseas fundraising arena was very different from the Israeli one, and that if I wanted to reach other communities, I would have to learn more about their specific culture of giving.

It was a great challenge to get people living far away from us to connect emotionally with a relatively unknown, fledgling organization, one that served a small number of people and was not well known even within our local community.

Thus we realized early on that we had to find ways to gain visibility and exposure for BIS as a leading force in the field of disabilities in Israel, and this meant that we had to change from being a local organization with a limited impact, to becoming a national organization with the power to benefit hundreds of thousands of people with special needs – and their families.

We analyzed our potential base of friends and supporters and challenged ourselves to reach out to every possible connection. This was the beginning of our ‘circles’ approach and became the basis of all our marketing. We analyzed our circles of influence into impact groups: family, friends, academia, service providers, government and semi-government contacts, boards and donors – and from there tailored our approaches to what might be of special interest to them.

I also understood that without actually traveling abroad regularly, I would not succeed in reaching our goals. Indeed, for the next 30 years I was to spend a great deal of my time away from home.

Management Challenges in Developing Global Fundraising from Israel

Building an organization in Israel at the same time that I was developing a global network of support (long before the internet!), was daunting.

One of the first and most critical steps I took, was to employ a US national consultant, the late Lucy Strauss, who served as my teacher and mentor for nearly 20 years and provided inestimable guidance for the American initiative until her retirement in early 2008 due to illness. Her input included teaching me the US

culture of fundraising and the legal requirements in the US and Canada. She provided direction on financial and administrative issues, taught me professional resource development and helped develop lay leadership. In addition Lucy supervised the professional fundraising staff working for our American Friends. Lucy became my close friend, and everything written in the rest of this chapter serves as a testimony to her impact on me.

The following sections will discuss our initial orientation to global fundraising, and the complexities of setting up and working with lay leaders and professional resource development staff in offices overseas.

Orienting to global fundraising

Beit Issie Shapiro was one of the first Israeli non-profit service organizations to open a fundraising entity abroad. Fortunately, we had access to funders overseas (primarily family) who were committed to our cause and were willing to introduce us to their friends, but no less important was the fact, that while the government provided minimal funding for services for special populations like ours and other non-profits made do with this funding, we knew that developing a high standard of services to meet the real needs of the people, would require a far greater level of support. Since we knew that the tradition of giving was more developed abroad than in Israel, it made sense to reach out globally.

However, fundraising abroad created many dilemmas - including, first and foremost, the great cost of running an overseas office with a professional staff while bringing in enough money to warrant this. We knew that we would not be able to develop a fundraising program without some investment, but tried to keep our costs to a minimum, so that we could transfer most of the money it raised to Israel. This issue challenges us to this day.

Another challenge was our inevitable competition with local needs, and the conflict many donors experience over giving to another country when their own community's needs are so great. I always related to this issue, on the one hand by suggesting to our donors that they give with their "Israel" dollars rather than by spreading their local charity budget ever more thinly, and on the other hand by ensuring that we develop our special area of impact. We have also always looked to develop projects which would have a mutual benefit to BIS in Israel and to the local community.

Fundraising overseas was also highly affected by economic issues and other local events. On more than one occasion, we had to change our campaign due to unexpected contingencies, including hurricanes, earthquakes and fires, which

affected the public's concerns and their dilemmas about giving to Israel when there were pressing local needs. On more than one occasion I remember stopping a direct mail fundraising appeal that had been prepared, and substituting it with a note to say: "We are thinking of you during this challenging time in your lives and praying that you and your loved ones are all well and safe".

Our overseas fundraising abroad required a high level of "organizational readiness" and support from our Israeli office. When we raise money in Israel there is easy real-time access to hands-on information. In contrast, long-distance fundraising required a well-constructed strategic plan supported by flexible documentation that clearly and concisely expressed our population's needs and told our story in imaginative, emotional ways.

In the setting up phase of a new fundraising office or "friends" group, there are many technical and bureaucratic details that have to be handled. In each region, our extended family was the forerunner of creating friends groups and activities to launch the Beit Issie message. In the United States, through the efforts of the Trump family, we registered the American Friends and developed friends groups in New York and Florida. In Los Angeles, Errol and Pat Fine, brought our organization closer to the LA constituency. In London, Steve and Gillian Martin, together with Karen and Anthony Beare, and Derrick and Ariela Beare, assumed initial responsibility to launch our friends group, dealing with the technical and outreach issues, while in Canada, Barbara Abrams assisted us in registering the Canadian Friends and introducing us to her friends – later to be joined by Trevor Stein, who became the president of the Canadian Friends, bringing with him an entirely new constituency of friends. Today we are proud to have a young generation that has become active in Toronto for us.

In the United States, Canada and the UK, donations are recognized by the tax authorities and the donors are eligible for tax deductions on submission of an official receipt from the charity. In South Africa, we were recognized by the IUA- the Israel United Appeal, and the monies were transferred by the South African Zionist Federation within the authorized permit granted by the South African Government.

Setting up and working with offices overseas

Traveling from Israel abroad on a regular basis is essential to connecting with existing donors and nurturing new ones. It also became clear, that without having a permanent presence in each country, our ability to become a well-known and supported charity would be limited. It was important to open offices in different regions and to hire professional staff to work as our agents.

The establishment of offices made it possible to develop a strong grassroots network of support and to professionalize our resource development strategies. However, these professional staff could only do their work, supported by an Israeli office – or ‘desk’ providing administrative services, documentation and a wide range of P/R and fundraising resource materials. Over the years this Israeli International Resource Development Department has provided an essential partnership with the overseas offices and donors, and has played a pivotal role in our success abroad. Also, having the international fundraising director working out of Israel has been an important factor in managing and integrating the global fundraising efforts, as well as having a hands-on and intimate knowledge of the programs at Beit Issie Shapiro, albeit it is very demanding on the professional.

Following are some key management issues that we confronted in developing our overseas resource development function: volunteer vs. paid staff, training staff abroad, developing involved and committed boards, communicating with the overseas office, handling visits and missions, positioning of global resource development in the home organization, database development, and communications with donors.

Volunteer vs. paid staff

Working with volunteers together with a paid staff raises significant managerial issues. While one may have expectations of staff, who are remunerated financially, one has to deal with volunteers in a different way: one requests assistance or services from volunteers and has to work hard to keep them involved, interested and excited. Sometimes this difference generates resistance. Volunteers may expect the staff to handle certain issues such as the administrative underpinnings of their campaign, while the staff may wish the volunteers would become more autonomous and accept more responsibility.

Ensuring a smooth and ongoing flow of information between the regional offices and the head organization in Israel is always a challenge, but more so when the branch is managed by volunteers who do not understand the necessity for feedback nor have the time (or interest) in administrative functions.

Nevertheless, building a team of volunteers is essential to the success of the operation. Not only can they supplement the work force, especially when the operating budget must be kept small, but volunteers who feel passionate about the cause, will spread its message to their friends and family and gain great satisfaction from their contribution. A vital part of the professional’s role in each location is to recruit, support and nurture volunteers who are not only willing to undertake hands-

on roles but who will take a leading role in the fundraising process. The process requires a great deal of patience and good will.

Expectations from 'volunteer' offices are different than from those that employ a paid staff. For example, if at any time income requirements are not being met, 'demands' can be made on professional staff to organize an additional fundraiser or expand their outreach activities, whereas in locations where their activities are coordinated by volunteers, 'suggestions and recommendations' may be made, but the volunteers may have many other commitments and not wish to take on further responsibilities.

In many areas such as South Africa, where we did not have professionals working for us, the demand of time and effort from myself and our local Israeli staff was so great, that we had to ask ourselves whether there was a purpose to conducting a full campaign when there was no professional team to carry it through. I learned quickly that without having a professional to lead the campaign, its success would be limited.

Fundraising training

Both staff and volunteers have to be educated about the organization, its mission, the people it serves and benefits, and its aspirations for the future. For the staff to feel confident in the volunteers it is imperative to ensure that they can articulate the organization's policies and values and understand its needs and difficulties. Only then can they be empowered to work on the organization's behalf.

To this end we provided regular training for our staff, both in Israel and abroad. For many years, we have held annual training sessions in the United States with the regional staff including the Canadian professionals meeting for 2-3 days to be updated about the organization, discuss their difficulties in meeting their fundraising targets, share ideas and develop cooperative ventures. On a number of occasions we brought in professionals to provide specialized training.

In addition to holding joint workshops and providing training abroad, we also brought staff to visit Beit Issie Shapiro on an annual basis, keeping them totally up-to-date and connected with the 'soul' of the organization. We also invested in training our volunteers, especially our lay leaders.

Board development

One of the main challenges of a global fundraising operation relates to the development of the lay leadership. A key component of any successful overseas

campaign is having a dedicated Board of Directors comprising people who are well-known and connected, who are willing to make personal contributions and agree to become agents for the organization.

Today a tremendous number of Israeli organizations fundraise globally, and the competition for funds is fierce. How do you connect people to your cause and inspire them to take on a Board of Directors responsibility? This was the main challenge of my work over the years.

A major issue that often affects overseas boards is that they are given responsibility to reach certain target sums, while they themselves can make little impact on the organization's decisions and plans. While they play no role in developing the organization's expense budget, they are nevertheless expected to raise the funds to implement it. The Board needs a greater sense of involvement and contribution. This issue is part of the task that the international resource development director has to deal with, and we are lucky to have good board leadership who feel connected and involved with the organization's mission.

Legally, the regional boards are empowered to dictate their own fundraising strategy and be responsible for the results. The Board can initiate local programs for education and cultivation as well as fundraising events to meet budget goals. But their activities have always to be tempered by the practical realities of a small staff, the need to keep their costs down, and the cost-effectiveness of their projects. Since 'people give to people', the route to getting the Boards to meet their financial goals is to get them to commit to the organization's goals, to be knowledgeable about the mission, to be able to tell the story about why the funds are needed, and to share this with their peers.

How to accomplish this has remained an ongoing challenge. On my many trips abroad, essentially to the United States and often to Canada and the UK, I would always contact the members of the board, visit them and participate in meetings. I saw it as my responsibility to constantly inspire them about the meaningful work we were doing and the many people who were benefiting from their involvement. It is essential to keep the members connected to the cause, knowledgeable about our progress, programs and achievements and enthusiastic about their investment in the organization.

We also made sure that whenever our professionals visited our various regions abroad, either to present papers at international conferences or for diverse consultations, they would attend board meetings and make presentations about their work. This of course helped reinforce the bond.

Visits and Missions

There is no doubt that the ability to have Board members see the local facility in action and meet their Israeli counterparts has been the most useful tool for building a close understanding and commitment to our cause. The visit to the Center is the key to ongoing commitment to Beit Issie Shapiro and one of our most important messages to all we meet abroad is: "Visit us when you visit Israel".

Guests are given 'red-carpet' treatment. In 1999, 'The Mission of a Lifetime' brought 30 donors and others to Beit Issie Shapiro for a week-long educational and social experience. Most of the participants in this mission have become committed friends and major donors to the organization and have taken leading roles in our activities.

A second successful mission, planned and carried out by Beit Issie Shapiro's Executive Director, Jean Judes, Benjy Maor – Director of International Resource Development, and the lay leadership in Israel and abroad led by Sasha Weiss, was the 30th Anniversary Innovation Summit, held in 2010 with 64 participants from many countries. The Summit added a new dimension to Beit Issie Shapiro's fundraising outreach, emphasizing the innovations and breakthroughs made by the organization over a thirty year period, and drawing attention to its social entrepreneurial approach through which we effect broad social changes to benefit the greatest number of people.

When planning visits of our overseas donors, preparing for the visit is no less important than the visit itself. The regional directors need to inform the local staff that the donor will be in town, when he/she might be available and how he/she can be contacted. The visits of high-profile donors might occasion a press-release or media publicity. The whole staff community needs to be briefed about the visit. Follow-ups are equally important, with the Israel office providing feedback to the regional office, making sure that visitors are on the mailing list, writing thank-you letters and following through on pledges made and terms of payments, etc. Of course, the most significant part of the visit is when the donor is able to see firsthand how his/her donation has been used – by seeing the children, sometimes meeting with parents, and hearing from the staff about the particular program that they sponsor.

Positioning of Resource Development in the Organization

The coordination of donor visits and missions poses the question of how the resource development office/staff is best positioned vis-a-vis the home organization: should this function be kept separate from the organization, or should resource development be integrated within the organization? To whom do the donors belong: the regional

office/fundraiser, the local office that hosts the visit, or even the professional whose project the donor funds? Who will take responsibility for nurturing and developing the donor's connection to the organization?

We decided that although overseas fundraising offices needed to be separate and autonomous, the department should be fully integrated into a global development policy. An international department was established at Beit Issie Shapiro to develop campaign materials - written and pictorial documentation that told the story in a way that would evoke interest and prompt giving - and provide the administrative follow-through to support outreach abroad.

In addition, rather than create a new "friends" organization in Israel, we integrated an Israel fundraising department into our service organization, and our professional resource development staff continues to work within the organization's parameters.

Database

A critical condition for success in resource development is having an efficient database to store, organize and analyze information about donors and donations. It has taken time and considerable trial and error to arrive at our effective and user-friendly database. Luckily for us, the US has been a number of steps ahead, and we have learned from their expertise.

Our first database in the US was called Q&A, and was set up by Lucy Strauss. This became our basic tool for collecting information about our donors and their giving history. As technology improved, we needed a more efficient and modern database and we acquired the Raisers Edge fundraising tool, which later became our global database. Today our staff is well trained in using this database and we are constantly improving the synchronization and communication between our offices and systems.

Communication with Donors

Working with people overseas requires active nurturing and cultivation, and it was clear to me that it was essential to communicate with our donors frequently, telling them about the organization, its progress, their particular projects being sponsored, our successes and impact. Over the years we developed many vehicles for doing this, including:

- Regular personal communication through mail and emails- I made it my business to ensure that I would sign personally the letters and personalize each letter or note according to my special relationship with the donor. In this way, I sought not only to connect with our donors but to nurture ongoing friendships for the

organization.

- Telephone calls to give reports, before the holidays, and on special occasions.
- Invitations to visit when they were visiting Israel.
- Scheduling visits with donors when I was in their vicinity, always following up with a personal letter after each meeting.
- Regular newsletters with up-to-date information on a global level, featuring pictures of their visits and projects in the newsletters.
- Invitations to events in Israel and abroad with personal thanks to each and every person who attended.
- Recognizing gifts in our newsletters, putting up plaques in honor of significant contributions in our building and publicly acknowledging donors on our website.
- Providing donors with regular reports on how their gift was used and who benefited from their contribution.
- Certificates of appreciation.

An important additional focus of communication has been sharing pleasure in Beit Issie Shapiro's achievements, honors, awards, presentations, etc. Such communications contribute to our donors' pride in being associated with our organization. This is critical to generating enthusiastic support overseas.

With the introduction of social media and the use of our website, we now have an ability to have far-reaching and timely communications on a very wide scale.

Professional Approaches and Campaigns in Beit Issie Shapiro's Global Fundraising

While the previous sections discussed the managerial issues we faced as an Israeli organization setting up a global fundraising network, the next sections will focus more on challenges we faced as resource development professionals, and upon some of the campaigns that have been particularly successful. Specifically I will address nurturing commitment with potential donors, key campaigns for building committed donors, cultivating major donors, and cultivating professional connections.

Creating Bonds of Commitment

One of the most basic of our professional challenges is captured in the following question: How would we create a bond between the good-hearted people in other countries and the children in Israel who were invisible, anonymous and so far away?

While hosting film premieres' and other events would always provide short term solutions, these efforts would not build long term donors who would make repeated and growing gifts. For this to happen it would be essential to turn these events into opportunities to tell the organization's story and elicit continuing sympathy and interest for its cause. The challenge was to bring the children alive in the imagination of the audience and to create mechanisms for good follow-up.

As an experienced community organizer and resource developer, I was always more concerned with building long term friendships than achieving one-off donations. I believed in the basic fundraising truism that people give to people rather than to organizations. So I set about making friends, inspiring them with my story and seeking ways for them to become personally involved.

I believe that initially many people gave to Beit Issie Shapiro because they liked and believed in me, and appreciated the intensity of my passion. They appreciated our commitment to use their contributions to make a difference, and they valued our commitment to total transparency - the fact that we were always willing and happy to share financial and other information with our donors. However, my long term goal was always to cultivate a connection with the organization or a project because of its intrinsic value rather than through any loyalty towards me as a person. In 2000 I wrote in my introduction to Beit Issie Shapiro's Fundraising Handbook¹: "It is not good enough to turn people on and inspire them to give to your cause because of the excitement you generate in them. The art of fundraising includes the art of moving people from giving out of loyalty to you, to committing themselves to the cause. Not only to play a minor role, but to become empowered to make greater contributions and take on positions of responsibility. Not only to become leaders but finally, to share our responsibility and commitment to finding solutions to common problems - to move people from involvement to empowerment to ownership."

Indeed, many donors did progress from making small donations to hosting events, participating on management boards, visiting the organization, celebrating special events with the children at Beit Issie Shapiro, providing capital gifts and even leaving bequests in their wills.

Campaigns for building committed donors

The Milestones Campaign

One of the most successful campaigns for building committed donors in the USA

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1. Bacher, S. & Stuchiner, N. (2000) Resource Development Handbook - A Practitioners 'Hands-On' Guide, unpublished document.

has been our Milestone Campaign, which offers a range of opportunities for families to involve themselves with the children at Beit Issie Shapiro at different stages of their family's development. The issue of Milestones relates to giving through the ages, and encouraging philanthropy from a very young age through to the older generation.

Cycle for Smiles

The Cycle for Smiles (CFS) Campaign targets families of very young children and was the initiative of my lifelong friend, Margie Ipp, who directs the Temple Judea Nursery School for typical children in Los Angeles. Moved by the difficulties and disabilities of the young children at Beit Issie Shapiro, Margie developed the first "ride a bike for a buddy who can't" project, encouraging her colleagues to join her in this quest. This led to the establishment of the CFS campaign that eventually became the main grassroots fundraising vehicle in California and elsewhere. This was especially significant in California where it was problematic gaining visibility for Beit Issie Shapiro, in a very spread-out community. Using outreach to over 40 nursery schools within the Jewish community, gave Beit Issie Shapiro major exposure to a very broad population.

The CFS campaign has been a wonderful vehicle for teaching the children and their parents about children with special needs and imbuing them with the value of "tzdakah" – giving to charity - and responsibility for their people in Israel. Children ride their bikes one day a year, cheered on by their parents, and contribute all 'sponsorship' monies raised to Beit Issie Shapiro. The program was further developed by Amy Slater-Ovadia, who worked at Beit Issie Shapiro in Israel as a volunteer coordinator and grassroots resource developer and later relocated to San Francisco. Amy took over the CFS project, using it to tell the community about the work being done at Beit Issie Shapiro and gathering friends throughout the city and beyond to support the cause. This project was developed further as Miles for Smiles incorporating children throughout their elementary school years encouraging their tzdakah after they had graduated from the earlier nursery school programs.

Project Ahava

Another one of Beit Issie Shapiro's primary campaigns for gaining friends in the USA has been Project Ahava, in which donors are asked to sponsor an educational or treatment program of an Israeli child. The success of the campaign rests on our ability to link the donor with a particular child in Israel – a child who is identified by name and picture. The main vehicle for finding supporters has been through small

get-togethers in private homes, hosted by friends. This project was initiated through one of our donors in New York, Sunny Goldberg, who named the project herself expressing that what we were looking for was a group of people who would show love to our special children. Sunny and Brad hosted the first dinner party in their home inviting people to become Project Ahava donors. I remember sitting at the dinner table with a picture of a child with his story placed on the plate in front of all the guests. Before dinner each guest committed to sponsoring the basic treatment program of one child at our Center.

Today support opportunities range from \$500 per year to \$25,000 annually, with most supporters being in the \$500-\$1000 range. Project Ahava has been a highly successful fundraising/friend-raising vehicle. With almost a hundred children receiving full day care and treatment at Beit Issie Shapiro, it has the potential to raise over two million dollars annually.

Project Ahava's success is in no small part due to the intensive and sustained support given to it by the International Desk staff at Beit Issie Shapiro. The children are individually identified, photographed and sponsored. Each donor receives information about his or her sponsored child's therapeutic program and progress and over the years many families have developed meaningful bonds with "their" special children, visiting them and sharing special events with them in Israel.

Over eight years ago, two wonderful youngsters, Jackie Cohen from the USA and David Martin, a cousin from the UK, decided to donate their bar/bat mitzvah gifts to Beit Issie Shapiro. As a result of their generosity, in 2005, Beit Issie Shapiro launched a special Bar/Bat mitzvah twinning project, in which thirty children – mostly living abroad – would share their bar/bat mitzvahs with Beit Issie Shapiro's children. They did this in various ways: some twinned their celebrations with the Israeli child and family, others sent special gifts. A magnificent quilt was created to commemorate these children's gifts, by a group of very talented volunteers, the Ra'anana quilters association. The quilt, which is a work of art, shows pictures of each of the donor children and a special inscription. The quilt is proudly displayed in the foyer of the Trump International Institute for Continuing Education in Developmental Disabilities of Beit Issie Shapiro. Since then, over 70 youngsters worldwide have joined this project, connecting themselves to the special children of Beit Issie Shapiro. Their gifts are now recognized in the center through new beautiful "friendship dolls' mini-quilts created by the same quilt volunteers.

For a campaign such as Project Ahava to succeed, it is necessary for parents to allow their children's pictures and information to be shared with sponsors. The problem was that back in 1986, when this program was initiated, many parents were very reluctant to sign the confidentiality releases which would permit such information to be publicized. Over the years this situation has fortunately changed. Today most parents allow Beit Issie Shapiro to share information with donors abroad as well as in Israel. It is a tribute to their growing confidence in the organization and the spirit of greater openness and public acceptance of people with special needs that Beit Issie Shapiro has worked so hard to achieve.

Project Ahava has been an excellent tool for recruiting donors, maintaining their interest and support and upgrading their contributions from time to time. It has also been an excellent medium for facilitating a meaningful connection between the American and Israeli children. Today several schools in New York and Los Angeles annually undertake to support a child. They make sure to visit Beit Issie Shapiro when they come on educational tours to Israel.

Special events

One of the challenges for non-profits worldwide, is that people feel that they just don't want to attend another dinner — we all are being faced with looking for something different that would engage the interest of our friends, and would bring them out of home to attend.

In New York, we realized that a performance, rather than a dinner, was the way to go and we started having events on Broadway, and off-Broadway. One of the highlights was having Dudu Fisher at a special New York event for us, which was an amazing success. Dudu was one of the few artists who not only appeared on Broadway, but actually met my late Father in South Africa when he was a chazan in Pretoria. Another exclusive was when Mandy Patenkin, another great performer, appeared for us at a unique event in New York. We later bought a large part of the theater for performances including Oliver, Mary Poppins and others, all which were great hits. People were interesting in seeing the shows and were willing to pay a higher rate to make a donation. These kinds of events nonetheless have their limitations. Unless we were able to buy out the entire theater we were often prevented from making a fundraising pitch and there was no real way to tell the BIS story to the entire audience.

The highlight for me was when we had the privilege of buying out the theater for Golda's Balcony, starring Tova Feldshuh, and later when she appeared in the moving play "Irena's Vow". I had my moment, when I was called to the stage to make a

presentation to Tova in front of a full house – what a special and rare moment this was for us, and I was delighted to be able to present Beit Issie Shapiro to a Broadway audience!

The New York board later decided to invest in family events bringing together three generations of our donors, who came with their children and grandchildren to a fun-filled day to benefit Beit Issie Shapiro.

In Florida, a major donors dinner was hosted each year by wonderful friends of BIS in their home. The select guests were treated not only to a magnificent dinner but also a viewing of their renowned and exceptional art collection. This major donors dinner has become an annual event and has been expanded to include a young family event with the next generation having a fun day for their children at the Trumps hotel resort in Miami.

In Los Angeles, our gourmet dinner event was hosted by Errol and Pat Fine at their stylish restaurant and it is always a major attraction. Over the years, we would bring a parent to talk at these events, and on occasion even had a guest speaker such as Cheryl Saban, who is also a psychologist and who had a professional connection to BIS.

A wonderful event in London is the annual HOD (Hebrew Order of David) bingo event which is hosted by Alex Beare, and where BIS, together with a number of other organizations, benefit from the proceeds. This is a good way to work collaboratively while spreading the message and getting support from the UK community.

One of the highlights that became a regional event globally was when we celebrated our 25th anniversary for Beit Issie Shapiro. In each region, we had a signing of a Charter of Rights of Children to Services, specially prepared for the 25th anniversary. This Charter also launched our 25th anniversary endowment campaign. Each donor was presented a beautiful Frank Meizler mezuzah inscribed with the Charter. There is no doubt that celebrating these kinds of milestones or special event adds an extra touch and incentive to donors to give us additional funds.

Celebrities for Beit Issie Shapiro

Not often does an organization in Israel have an opportunity to interest major film stars abroad. Through the good auspices of the late Jaapi Kroonenberg, Sophia Loren agreed to participate at a major fundraiser for Beit Issie Shapiro in Amsterdam. I had the privilege of traveling in a cab with her to the event and I told her all about our work. She made a moving speech about our children at the elegant dinner held to honor both her and BIS. That evening we raised a large amount of money and much

good will for Beit Issie Shapiro. Unfortunately, she did not accept our invitation to visit us in Israel.

This did not stop us from inviting former President Bill Clinton to be our guest of honor at our 25th anniversary event in Jerusalem. To our great pleasure he agreed to come and the inspirational words he shared in his speech moved every one in the audience.

"If you see a child with a mental or an emotional challenge do you see them or do you see how you feel in your worries and fears about them?

You can change and enrich the quality of this wonderful nation even more by getting people to ask and answer those questions, and in so doing, you can be a model for the entire world.

All the people on earth have something from which we can learn and something they can give. "

There is no doubt that this event was a turning point for us in our fundraising outreach both in Israel and abroad.

The "Generation Next" Campaign

One of my major concerns has been to ensure the future sustainability of Beit Issie Shapiro. In my own personal family, it was clear that our children and grandchildren would have a personal commitment to continue the family legacy. However, as Beit Issie Shapiro is larger than one family, we are always been mindful of the importance of bonding with the donor's family instead of restricting its warmth to the individual donor. The "Generation Next" Campaign which involves members of the next generation and their friends is telling proof of the success during the past 30 years. Nothing is more gratifying than to see the children and even grandchildren of longstanding donors visiting Beit Issie Shapiro and becoming personally and actively involved. And of course, this gives us a real sense of continuity for Beit Issie Shapiro into the future.

Cultivating Major Donors

Parallel to developing a broad base of grassroots support, Beit Issie Shapiro cultivates the involvement of individual and organizational donors with the potential of funding capital intensive projects such as building development, endowment programs, national programs, community outreach work, research and training initiatives.

Beit Issie Shapiro's philosophy is that if a project is worth developing, every effort should be made to fund it. Working in partnership with donors who have the

foresight and resources to invest in innovative programs which break new ground is always rewarding. The Jewish Federations, Foundations and Philanthropic Trusts have played a key role. A number of the foundations supporting us have enabled Beit Issie Shapiro to create programs with far-reaching impact. Our greatest satisfaction is when our major donors become involved beyond their financial investment and take a personal interest in the development of the project and its successful implementation. These investments have had a major impact on attitudes and services throughout the country.

Cultivating Professional Connections

Another development that provided leverage for attracting funding, was our professional outreach abroad. This helped us establish BIS's reputation internationally, gaining legitimacy for our work and the confidence of donors.

In 1992, the American Friends of Beit Issie Shapiro (New York) established a Professional Advisory Committee (PAC) comprising experts in services for children and adults with developmental disabilities. Its primary role was to co-host and form a scientific committee for our quadrennial international conferences and in this capacity it has served five conferences - in 1994, 1998, 2002, 2006 and 2011. Through the efforts of its members, Beit Issie Shapiro has been able to make important professional connections and partnership that has attracted the interest of major Foundations, gaining significant funding towards development.

With Beit Issie Shapiro's evolution from a local to a national and even international organization, the role of the PAC has assumed greater importance. In 2011 Beit Issie Shapiro enjoys the support and collaboration of professionals in the USA, UK, Canada and South Africa. These groups provide professional advice, guidance to further liaisons and affiliations with organizations abroad and participate as advisors in the planning of international conferences. In addition, they contribute by networking, keeping staff informed of new trends, research and training opportunities.

Conclusion

Beit Issie Shapiro's model for global resource development is based on the principles which shape all the organization's efforts: a belief in the strengths and resources of the community, a process for identifying problems and solutions, and creative and persistent efforts to harness the strengths, commitment and energies of people who want to make good things happen.

From the outset Beit Issie Shapiro has been an international organization. Our recognition of the impossibility of local financing for the high standards of service we wanted to provide, and for the society-wide change we sought to promote in Israel, propelled us to seek support abroad. Simultaneously, my father's family, friends, and many admirers provided us with our initial opportunities. Over thirty years ago I made my first trips to South Africa and the United States, then to Canada and the UK, to invite these people to join us in developing a living testimony to his memory.

There is an interesting synergy between our global fundraising efforts and Beit Issie Shapiro's development. Beyond the obvious financial benefits of the donations, the drive to demonstrate to so many good people that our cause was so unique and worthwhile that it deserved their special commitment pushed us continually to excel in all that we did. It was not enough to provide excellent professional treatment; we needed to excel in our management strategies, in our performance at every level, in our clarity of mission and communication.

It has often been an exhausting journey, but one that I feel privileged on many levels to have taken. One of the most deeply rewarding aspects of my experience has been the opportunity to develop friendships with our donors. How could I not be in awe of having met so many amazingly generous people, all of whom were willing and happy to support our mission. I treasure these relationships and am grateful for having had the opportunity to facilitate the connection between these many wonderful people and Beit Issie Shapiro.

V

The Role of the Extended Family

A Family Perspective¹

Orli Cohen², granddaughter of the late Issie and Lucie Shapiro (of blessed memory)
and daughter of Tuvia and Naomi Stuchiner

In my childhood memories, it all started one late night when the phone rang at home, and heartbreakng cries were heard. Grandpa, our grandfather, Issie Shapiro, died suddenly in the US, and Granny, Lucie, called to give the news of his death.

I was just a 7-year old little girl, and I already understood that nothing in our lives would be the same again.

I didn't have the privilege to know my grandfather, Issie Shapiro, very well, but behind this man, there were many stories and we grew up on his legend.

The decision taken during the "Shiv'a", to establish a place in his memory, started to become a reality, and I remember as a little girl the place in Herzliya. While it is true that as children, we used to visit the residents of Shikma and Kfar Nachman, this time it was different. This time our "visit" didn't end – the new place called Beit Issie Shapiro was here to stay.

Mom very quickly became committed to this new project, as she did with everything else in her life. She was determined to succeed and to make it happen. Now, when I write these words, I notice that I could be writing about a new baby (something I already had experience with), but this was mostly Mom's baby, at least until Dad gave in and joined her in the venture: "If you can't beat them – join them."

OK – I could speak about "sibling rivalry", about combining career and parenting, or any other issue that could provide many good psychologists with a good livelihood,

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1. This chapter is based on the speech made by Orli at the seminar "Closing the circles – 30 years of social entrepreneurship" that took place on 26th January, 2011 to mark the retirement of Naomi Stuchiner from her executive roles at Beit Issie Shapiro.
 2. Orli Cohen, B.S.W, Financial and Personal Coacher, with ten years management in health systems. Currently qualifying towards MBA in Social Leadership at Ben Gurion University.

and probably interest many of you, but I won't do that.

I want instead to speak about how we benefited as children from our new sibling.

We don't always understand why things happen, or how, and what God has in mind when he works in one way or another. Moreover, not infrequently I have asked myself: What would have happened if we hadn't received that fateful call that night? I couldn't imagine my mother without Beit Issie Shapiro or Beit Issie Shapiro without my mother. There are people who are destined to do something in their lives, and they will not rest until they accomplish what they have set out to do.

My mother raised both us and Beit Issie Shapiro out of an absolute conviction that if you want something badly enough, it will happen. You will work, sweat and pray and at the end it will happen. And each time someone told her it was impossible, she tried harder – there is no word for “impossible” in her dictionary! If neighbors oppose – good, great, it is a sign that something is bothering them – why don't we try to bring them into the process and solve the problem that way. If there is someone up above who believes that children under the age of 3 don't deserve services – no problem, we will pass a new law!

Mom's way has no barriers – only challenges – and they always become her next goal.

But what was the foundation that nourished this battle? What was the driving force? To me it is clear: the VALUES – the values which have passed as a legacy in our family from earlier generations, from the highest oaks through the knotted roots. Those who knew my Grandfather and Grandmother, Lucie and Issie - whose home was open to all; whose hearts heard each needy voice; and whose pocket opened to everyone who stretched out a hand – know about the education my mother with her brother Max and sister Esther were privileged to receive. This same education has been passed on to us – the next generation. Not by chance those who are on the periphery will always be at the center of the focus of our family. Putting their rights on the public agenda resulted in these children becoming entitled to equal opportunities and receiving the treatment that they deserve in the best possible conditions available.

Our mother taught us that there is no ‘half’ and no ‘approximate.’ Her perfectionism and drive for wholeness, is evident not only in the tasks that she undertook, but also in her world view. The world has to be perfect, and if it isn't, then we will simply fix it. In a world of lies, there has to be truth, in a world of injustice – justice, and in a world of alienation – love.

One of the values my mother considered important, was the principle of ‘inclusion’ – of helping children with special needs feel included and part of the community.

Thus it was natural that our children would grow up in Beit Issie Shapiro and absorb its atmosphere from an early age. I have to share with you the story of my daughter Noa, who one day, when she was in first grade, came home after a visit with a friend and told us that she saw a strange thing in her home: Her friend's sister is older than her brother, and despite this, the sister wears a diaper while the brother does not. Since I knew that this child had Down Syndrome, I asked Noa if she noticed that the little girl was special. Noa looked at me with surprise and asked me – what do you mean special? I answered Noa that she is similar to the children at Beit Issie Shapiro, and then Noa looked at me and answered: Yes, but Mom, what is special about the children at Beit Issie Shapiro?

Mom – in my eyes, this is the story of your victory. When regular children understand that a special child is no different from them at least not at first glance – that is your unbelievable achievement!

To be honest, not one of us believed that our mother would put down the baton and leave Beit Issie Shapiro – we somehow imagined her getting to 120 sitting at her desk – and from there straight to Heaven.

We are happy that you have decided to slow down – even though we are still not convinced that this will happen. We think that you are right to allow your "baby" to grow wings and fly on its own – even though you will probably continue to watch over, just as you do with us, interfering only when it is entirely necessary.

We are hoping that now, finally, you and Dad will make some time for yourselves, even though it is quite clear to us, that even after your retirement from your incredible work in Beit Issie Shapiro, you are not finished contributing to Israeli society. And already you are busy again, fixing the world, for there is so much to be done.

So your retirement gift that would include a rocking chair, knitting needles, books and movies, will have to be put aside for a few more good years – because you cannot be stopped!

And one word to our Father – there are very few people who would be willing to support, advise and commit themselves to the vision in the way you have done. For us, you and Mom are a team, and even though this evening is dedicated to Mom, we take off our hats and salute you both with love.

Exploration of Issues Related to Founding Family Involvement and Executive Director Succession in Beit Issie Shapiro's 25th Year¹

Israel J. Sykes and Naomi Stuchiner

Introduction

Beit Issie Shapiro (BIS) is a not-for-profit community-based organization in Ra'anana, Israel, committed for the past 25 years to building a caring and responsible community in which people with special needs enjoy full rights and access to social, educational, treatment and recreational services. BIS provides a comprehensive range of services for children with developmental disabilities and their families, directly serving nearly 7,750 children and adults yearly. In addition to those it serves directly, it impacts significantly upon a much broader population through community outreach, volunteer programs, student training, research and development activities, professional training programs, and advocacy for policy change. Its partnerships with people with disabilities, with families, and with allies from different sectors of society (national and local government, not-for-profits, universities, business), have been a major factor in significantly raising standards of care in Israel for children with developmental disabilities and their families.

In 1999, Beit Issie Shapiro received the Prime Minister's Shield of the Child Award in acknowledgement of 20 years of excellent service to people with developmental disabilities in Israel. BIS is similarly recognized throughout the world as a pioneer in its field, as evidenced by three widely attended international conferences that it has sponsored and hosted.

The above description reflects the professional excellence, vision and social

1. This chapter was in Hovav, M. & Gitelman, P. (eds.) (2006). From Segregation to Inclusion: People with Disabilities in the Community, Jerusalem: Carmel Publishing House, pp. 397-418. (Published in Hebrew).

entrepreneurship of BIS's leadership and staff, the dimensions usually emphasized in publications and public relations material.² Another critical aspect of BIS's success, however, has not yet been explored and explicated: Established by a family in memory of their brother and father - himself a pioneer and entrepreneur in the area of services for children with special needs in South Africa – BIS is a rare hybrid of family enterprise and public service, as manifested in the following roles and contributions of members of the founding family:

- BIS's values, vision, mission and standards are the embodiment of a family legacy
- A family member, herself a social worker, has been executive director since the venture's second year
- Several additional family members have held key staff positions and are active members of the board of directors
- The extended family of founders is a major source of private funding, providing over \$700,000 annually to help develop and maintain quality services
- Four generations of extended family are actively involved in creating and developing an extensive international network of support.

In the past the role of the family has been an ever-present yet downplayed aspect of life in BIS, with explicit discussion of the family focusing primarily on the legacy of Issie Shapiro himself.³ At various points in the organization's development, tensions and questions arose among staff and in the community with regard to the appropriate role of family members in a non-profit organization. For example:

- Do family members have special rights and obligations (by virtue of history and funding)?
- What is the family's appropriate place on the staff and on the board?
- To what extent is family control legitimate?
- Does the next generation have an "inside track" to management positions?

These questions have for the most part been undiscussed and undiscussable undercurrents in the BIS culture. At times, though, they became the focus for more public and explicit attention, as in articles in the local press.

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2. Rosenfeld, J.M., Schon, D.A. & Sykes, I.J. (1995). Out from under: Lessons from projects for inaptly served children and families. Jerusalem: JDC-Brookdale Institute; Monasch, D. (2005). Naomi Stuchiner, house of love. Lifestyles Magazine; Stuchiner, N. & Sykes, I.J., (1995) Vision-driven management. Paper presented at the first international Beit Issie Shapiro conference.
 3. Stuchiner, N. (2005). Address at the 25th anniversary of the passing of Issie Shapiro.

This article signifies a first attempt to deliberately and systematically reflect upon and explore the place of the family in BIS's past and present, with the express intention of setting the stage for its future. It reflects the recognition, that the connection between the family and the organization can be an important source of learning for other families, services, and communities involved in civil society.

The current article will explore the phenomenon of family involvement in BIS by combining a literature review with an exploratory qualitative study based on in-depth interviews. First a brief survey of the literature will be presented to highlight the uniqueness of the BIS phenomenon, and the extent to which its parts are recognizable and have been studied in a variety of fields, but the whole seems to be as of yet unexplored. Secondly, a methods section will describe collection of qualitative data on the basis of semi-structured interviews with 10 key family and non-family members. Third, findings will be presented on the basis of themes that emerged from the interviews. Finally, these findings will be discussed and reconnected to the literature.

An overview of the Literature

A search of literature in an attempt to understand the phenomenon of BIS reveals several different research areas that overlap different aspects of BIS, but none that encompass it entirely. The extensive professional literature on services for children with developmental disabilities⁴ relevant to much of the professional activity that takes place in BIS does not recognize the roles of "founding families". To the extent that attention is paid to families, these are the client families.

Similarly, in the literature on the civil sector⁵ relevant to the non-for-profit status of BIS and to BIS's efforts to provide social services that supplement those provided by the government, and the literature on "social entrepreneurship"⁶ relevant to much of the entrepreneurial development of BIS, no attention is paid at all to the roles of social entrepreneurial families. Again, to the extent that families are mentioned they are always families who are served, not those who serve.

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4. Kurtz, L.A., Dowrick, P.W., Levy, S.E. & Batshaw, M.L. (1996). *Handbook of Developmental Disabilities: Resources for Interdisciplinary Care*. Gaithersburg: Aspen Publications; Batshaw, M.L. (1997). *Children with Disabilities*. Baltimore: Paul A. Brookes.
 5. Edwards, M., and Hume, D. (eds.) (1997). *Making a difference: NGO's and development in a changing world*. London: Earthscan Publications.
 6. Bornstein, D. (2005). *How to Change the World: Social Entrepreneurs and the Power of New Ideas*. Oxford: Oxford University Press.

Two bodies of literature that research phenomena directly related to families as agents of social action are those that focus on family foundations and family businesses. While some of the family relational issues that arise in family foundations, such as family legacies and extended family involvement, are similar to those in BIS, there is a basic difference between foundations and BIS, in that foundations start with money and face the task of identifying worthy causes to fund, while BIS is itself the worthy cause that the family rallies around to support.

With regard to the literature on family businesses, Chua et al⁷ surveyed the prevalence of different topics in the literature, noting several that are of great relevance to BIS, including issues of succession, work with boards of directors, transition toward professional management, and life cycle stages of family businesses. Nonetheless, there are likely to be very significant differences between family endeavors that are focused first of all on profit and income, and those that are focused on provision of social services and promotion of social change. These differences have not yet been explored.

One ethical issue relevant to BIS that has received preliminary attention in the family foundation literature⁸, and in the family business literature⁹, is that of nepotism. Vinton defines nepotism as the practice of hiring relatives, a practice that has received an increasingly pejorative connotation over the years. Kidder notes some ethical issues that arise, concerning nepotism: Is it right to invite family members to serve in key positions within a family foundation, since they have such a strong stake in upholding the legacy and intent of the donor? Or do such family ties create managerial entanglements that impede the smooth functioning of the organization?

Methods

Due to the exploratory nature of this study, the methodology chosen was qualitative¹⁰, based on semi-structured interviews with a small (n=10) and non-random sample.

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7. Chua, J.H., Chrisman, J.J., and Sharma, P. (2003). Succession and nonsuccession concerns of family firms and agency relationship with nonfamily members. *Family Business Review*, 16, 89-107.
 8. Kidder, R.K. (2004). Why did I make all this money: Values and ethics in family foundations. Institute for Global Ethics, www.globalethics.org
 9. Vinton, K.L. (1998). Nepotism: An interdisciplinary model. *Family Business Review*, 11, 297-303.
 10. Taylor, S.J., & Bogdan, R. (1998). *Introduction to qualitative research methods* (3rd ed.): A guidebook and resource. New York: Basic Books.

The researchers

The research team was comprised of the organization's executive director Naomi Stuchiner and Israel Sykes, an outside consultant/researcher who had collaborated previously at an earlier stage in BIS's development, during the years 1993-1995. During these years Naomi participated in a learning seminar that brought together the directors of eight social service programs that succeeded in serving "inaptly served" families, for the purpose of reflecting upon and documenting their successes and the lessons that could be learnt from them.¹¹ Following the seminar, Naomi continued to be involved in an ongoing learning group of project directors that Israel facilitated, and in addition the two met regularly to reflect upon issues relevant to Naomi's leadership and development.¹²

The fact that Naomi Stuchiner was both a key family member (Issie Shapiro's youngest daughter), and Executive Director of Beit Issie Shapiro since its second year and till the time of the study (24 years), meant that she had a great personal and professional investment and involvement in both family and organizational issues. This made her an important resource for the design of the study and for the analysis of the interviews. At the same time, the same fact could cause a certain amount of response bias, as family and organizational members may hesitate to speak openly on sensitive issues. This concern was addressed by having Israel Sykes perform the interviews, while interviewees were assured that documentation of the interviews would be shown to Naomi Stuchiner only after their approval. Five interviewees gave their approval at the time of the interview, while the remaining five chose to review the document to have the chance to make revisions prior to her viewing.

Finally, the study took place in an ongoing organizational context in which Naomi Stuchiner, as Executive Director, saw some of the issues raised by the study - including extended family involvement and Executive Director succession - as critical for the organization's moving into a still unforeseen subsequent developmental phase. It was hoped that the study - the issues it raised, the discourse it stimulated, and the conceptualizations it engendered – would contribute to the fashioning of the organization's next phase.

Interviewees

Interviewees were chosen to represent a cross-section of people in the organization,

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11. Rosenfeld, J.M., Schon, D.A. &, Sykes, I.J. (1995). Out from under: Lessons from projects for inaptly served children and families. Jerusalem: JDC-Brookdale Institute.
 12. Stuchiner, N. & Sykes, I.J., (1995) Vision-driven management. Paper presented at the first international Beit Issie Shapiro conference.

in order to elicit multiple perspectives on the issues being studied. Categories from which interviewees were chosen included family members, staff members, board members and chairpersons of the board. Ten individuals were interviewed, some of whom belonged to more than one category. Thus there were six family members, five staff members, one board member and the former and current chairpersons of the board.

More specifically, family interviewees were chosen who represented different generations and different forms of relation. These included:

- Max Shapiro and Esther Boyd, two of Issie Shapiro's children, founders of the organization. One of whom has been on the board throughout the years, and the other has worked on staff for the past four years (after her husband had worked on staff since BIS's founding).
- Giora Stuchiner, Issie Shapiro's grandson, son of the executive director, who has worked on staff in both voluntary and paid capacities. He is involved in fundraising activities abroad
- Saul Fine, a member of the extended family currently active in the activities of the next generation.

Staff interviewees were chosen to give different perspectives from within the organization and different historical perspectives related to when they began to work in the organization. These included:

- Jean Judes, the professional director and Deputy Executive Director of the organization, who came to the organization in 1993.
- Lili Levinton, Manager of day programs, who has been on staff since 1986.
- Sigal Winter, Manager of fundraising in Israel, on staff since 2000.
- Liat Baram, a social worker on the multidisciplinary staff of the day programs, previously a student in Beit Issie in 1994, and on staff since 2000.

Directors of the board have an intimate connection with the organization while their core activities are elsewhere. Thus they are deeply involved in key organizational decision-making, while at the same time they remain outside of ongoing organizational activities, giving them a perspective that could presumably supplement the perspectives of family and staff. The two interviewees included:

- Geoff Tolman, a prominent businessman, second cousin to the Executive Director, who was chairman of the board for most of the organization's existence.
- Caron Bielski, a younger businesswoman and prominent member of the community, not a family member, who began her involvement as a lay person in charge of local fundraising, went on to join the board and recently became chairperson.

The interview

A semi-structured interview constructed by the authors was comprised of five questions, designed to elicit statements about the meaning and place of BIS in the interviewee's life, and to look critically at the advantages and disadvantages of family involvement. In addition, a question was introduced related to succession, a highly critical developmental issue that the organization had begun to face. Specifically, the questions asked were:

1. How did you come to be personally involved in BIS?
2. What does BIS and involvement in BIS mean to you?
3. What advantages and disadvantages do you see in family involvement in BIS?
4. How do you think Naomi's passing on the job of Executive Director to a successor might influence family involvement and influence?
5. Do you have any other thoughts or comments before the end of the interview?

Interviewees were told that they were participating in a study on family involvement in BIS, that would be the basis for a chapter in a book, that would be published prior to the next year's international conference. They were provided a page with the questions, which were first presented as an overview and then addressed one by one.

The interviewer was actively engaged with each interviewee in an effort to understand both the perspective of the individual interviewee and the phenomena themselves. He posed the above questions, documented the responses, and asked additional questions with the purpose of helping interviewees to clarify their meaning. In the process, the interviewer arrived at insights that he posed to subsequent interviewees as hypotheses, in order to explore jointly their validity and significance.

Many of the interviewees commented during or after the interviews, that while the questions and the ensuing interview touched upon issues that were very important and relevant to their experience in BIS, for whatever reason they had not previously been the subject of explicit organizational discourse. Thus interviewees often had much to say, but a certain degree of probing was necessary to help them get in touch with and formulate their own implicit knowledge.

Findings

Analysis of the interviews points to the following categories according to which the findings will be organized:

1. Perceived advantages of family involvement for the organization.
2. Perceived disadvantages of family involvement for the organization.
3. Developmental crises related to family involvement and their resolution.
4. Shifts in the boundaries of "family" in the organizational culture.
5. Thoughts about the possibility of imminent Executive Director succession.

Perceived advantages of family involvement for the organization

Interviewees were uniform in their perception that family involvement brought significant benefits to the organization. The first and most obvious benefit comes from the financial support that has been provided over the years by the extended family:

Financial support from the extended family has given us the possibility to expand over the years. It gave Naomi the confidence to take risks.

It is clear that without family influence BIS would not have developed so well. The family also helps to generate non-family funding, by networking via family connections.

Family involvement and backing puts the financers close to the management, which makes it easier to get things done and make decisions.

Many of the interviewees related to different aspects of the family's caring and commitment, and to the added value that the organization derives from them:

There's a much higher level of commitment that makes the organization slightly different and more special than other parallel organizations. The family link gives a stronger backbone, people unify around it. The commitment of family members comes along with a commitment to maintain the organization's values and vision.

It's not that others can't be committed and give the best. We have had wonderful members of the board, but they come and go. This is our family's contribution to society and the line of continuity gives us an edge over other organizations.

Family members, with their deep commitment to the family legacy, are willing to take on and deal with problems and frustrations that would overwhelm other members of the community, who may care deeply but lack that special extra commitment.

Other interviewees referred to the advantage that family involvement gives to the organization in its efforts to mobilize support outside the organization:

The support of the family gives a kind of legitimacy and security in the eyes of others: It's an organization with its own backing. This makes a big difference to potential donors when we look for additional funding.

In BIS the core family has succeeded in bringing in the extended family, which makes the unit more far-reaching and powerful. Members of the extended family want to be involved, to contribute not merely money, but also their talents, abilities and connections on every level. It's like having your own ready-made group of volunteers to support you even before you go to the general community.

Finally, staff members related to the positive effects of family involvement upon the life in the organization:

In my experience, the intense family connection to BIS is a source of great organizational power. It does something to staff members on the level of the involvement of their own families in the organization. Our own children – and spouses - become involved in our work in a way that you see at few workplaces. BIS became home to the families of the workers (especially in the earlier years). Our children came to volunteer from a young age, in a very normative, taken for granted atmosphere. As they grow older, they work in all kinds of odd jobs. Our own families and friends are well acquainted with BIS. This does something to the organizational culture. There's something different in the relationships between employer and employee. We know each other's children, we've seen them grow up, and we love them like our family.

There's a familial feeling here. For all of us as human beings, it's easier to manage when you know that your family is behind you. When you feel that the future of the organization is guaranteed because of the support of the extended family, you feel more secure. Family is a matter of generations, of an essence that transcends the shorter term agendas of most organizations. Family is connected by blood, not merely by a contract, not only if there's funding. That's powerful.

Perceived disadvantages of family involvement to the organization

Interviewees tended to have less to say about the disadvantages of family involvement than the advantages, and required more probing by the interviewer. Disadvantages brought up after probing tended to be either potential ones that had not manifested as problems, or others that did manifest but, now belong mostly to the past.

A first potential disadvantage raised was that of organizational dependence upon the family for survival:

One potential drawback I can see for the organization is that this creates a

dependency on the family. BIS could not continue to function well without continued family support.

The second potential disadvantage that was raised in several interviews was that of nepotism:

Previously I have been afraid of nepotism charges, due to the hiring of family members. Accusations of nepotism, especially when they are based on truth, can be very dangerous to the organization.

In terms of disadvantages, I think the main issue is the potential involvement of family members as paid workers, who are less suitable than others for the position. I have not experienced this as a problem at all, but it's an issue that others might have had in the past.

More veteran staff members pointed to problematic dynamics in the staff related to family involvement that had been salient at an earlier stage in the organization's development:

The issue of family members working in the organization is a real dilemma, and it has created some uncomfortable situations. For example, being a boss to one of the Executive Director's family members can't be simple. It's impossible not to treat that worker differently from others, and there is definitely a risk that this can negatively affect work quality. What if the manager is not satisfied with the worker's performance, what does he do then? There are also situations in which family dynamics and tensions inevitably spill over into work relationships.

When I first came in there was a lot of suspicion and hostility about the family issue. People felt that being a non-family member put them at a disadvantage, that they were not and could not be equal stakeholders in a family run organization. They felt they were doing a lot of important work, but were not getting enough recognition because so much of the focus was on the family. Some people felt exploited, and this dynamic definitely hampered the development of the organization.

In contrast, an interviewee who joined the staff more recently reported none of these kinds of tension, noting instead:

In my work the family issue doesn't come into play at all. I am attuned to a different place. I feel free to work in accordance with my professional judgment, keeping in view the organization and its needs rather than the family. My tasks are matter of fact: who do I want to reach? Where do I want to go? The family does not dictate my agenda.

Developmental crises related to family involvement and their resolutions

Interviews with people who entered the organization at different times, like those quoted in the above section, revealed that over the past ten years there has been a significant shift in the way in which family involvement has been experienced in the organization. This shift can apparently be attributed to successful coping with developmental challenges faced by the organizational leadership as BIS expanded beyond its intimate core and as it faced hostility from elements of its environment. In the following quote the professional director and Deputy Executive Director provides insight into two of the factors that contributed significantly to this change - her role as a mediator at the boundary between family and staff, and the Executive Director's response to a crisis sparked by charges made against the family in a local newspaper:

Being at the boundary between family and staff, much of my job was to mediate between Naomi and the staff, working a lot with both sides to help them reframe how they saw the other, dealing with many tensions as they arose. I knew that if I was to succeed, I had to deal with this task. I had to stay emotionally differentiated and not be drawn in. It was probably the hardest aspect of my job in the first few years.

Even if I had my conflicts with the family, I had to be careful not to bring that to the staff. I had to be aware of this and work on it. When the staff had criticism of the family, such as defining things as nepotism, or feeling exploited, I had to help them see the legitimacy of the family's rights and perspective. Partly in response to this process, Naomi changed a lot over the years. She has become more able to let other people in to the family endeavor.

I think the crisis of the newspaper article in the local paper that charged Naomi and the family with nepotism and mismanagement was an additional critical factor contributing to Naomi's change. It caused her to do a lot of soul-searching that led to a different model of the issue of family, one that gave more space to the staff members. We started giving management and staff members more credit, more opportunities to be visible at events and in the media. Staff members got more exposure, and as this developed staff members increasingly felt that they were important partners in the family's mission.

The above quotes point to a process through which awareness of a need for change among top managers led them to give staff members and their contributions greater visibility and recognition. Another factor, that seems to have been critical to resolution of the tensions described above, apparently has to do with a critical shift having taken place in organizational discourse on the family, shifting from a

focus on the family of the Executive Director, to the much broader focus on the contribution of the extended family of which the Executive Director is a part:

The image of an Executive Director who brings in family members to work arouses one set of thoughts and feelings, and that of an extended family carrying on a father's dream to the next generation arouses an entirely different one. Seeing the role of the extended family has helped staff to move beyond the nepotism issue and to connect to the family's intergenerational commitment to the organization. Everyone here knows that members of the extended family are our biggest donors and supporters. We all have an interest that the extended family continues its commitment to the organization. Today we can say that the family is advantageous and essential. The organization would be in danger if it negated family involvement.

Shifts in the boundaries of "family" in the BIS organizational culture

The current study set out to explore the effects of the involvement of the founding family upon the dynamics and development of BIS, and discovered that a surprising shift in the very meaning of "family" in the BIS organizational culture has occurred over the past several years: The boundaries of "family" have expanded, not only to include a growing network of extended family, but going beyond the biological family to include an expanding staff, and to a certain extent the board members, donors, and the children and families of children served by BIS. This section will explore the meaning and scope of this change for staff and for the next generation of the family.

Staff: What it means to be a member of the BIS Family

Early interviewees from BIS staff, when asked to describe what their involvement in the organization meant to them, described the deep impact that their work in BIS had upon them and upon other members of staff, and attributed this in part to the familial nature of the experience. For example:

It's like people are part of a big family, the Beit Issie Shapiro family. There's a sense of belonging. It's not easy to work here, there are high pressures and demands. But this sense of family helps.

There's something very special about the connection between BIS and the people who work there. BIS does something to you, leaves something inside. It becomes a part of you, leaving an imprint in your identity, more than an ordinary workplace, and even more than one that is both professional

and committed. Everything takes on a different dimension: the relationships between the workers, the dynamics. It seems to be related somehow to the issue of the family, or to the familial nature of the place.

As this theme of the "Beit Issie Shapiro family" began to emerge in interviews, later interviewees were asked to explain how they thought this experience was created. It became clear that it was the result of a very definite, if not yet explicated, strategy of including the staff and their families within the definition of "family". This is manifested in the interviewees' experience in three separate dimensions:

1. Organizational support and backing in times of personal crisis

People here are made to feel like they're part of one extended family. For example, if a staff member is in mourning, food is sent to the house for a week. If staff members are sick, they are cared for, taken to treatment by other staff members, visited at home. When a family member of a worker dies, members of staff are all the time going to the house of mourning.

One of the important things that the family did to change the feelings of the staff is to set up an aid fund for staff members' families and a scholarship fund for higher education for their children. The organization has always taken care of workers in need. This has contributed to the feeling that the staff members are really part of the extended family.

2. Treating employees' personal and professional development as an important organizational priority

The organization gives a tremendous amount of support to its employees, constantly providing opportunities and encouragement for them to develop and grow in ways that are meaningful to them. At the same time, the organization expects its employees, out of their deep commitment to the shared vision, to dare making their professional and personal dreams come true in the context of their work.

Beit Issie is my home both on the personal level, and also in terms of the opportunities it affords for me for professional development. The organization gave me, and still gives, lots of room for creating thinking, development and initiative, and there is a physical and human infrastructure, that makes it possible to make dreams come true. Beit Issie enables me to get up each morning and do the things that are most important to me, my heart and soul.

3. Expectation of wholehearted identification with and service to the family mission

Being a member of the BIS family means living with a strong expectation for

a wholehearted identification with and service to the family mission. It is not enough just to do your job as a professional. Every employee is expected to contribute in some way to fundraising efforts, and to be a BIS ambassador to the outside world.

It's interesting that Naomi is looking for her senior staff to be partners. What is that really, what does she want? Beyond your being a top professional, serious and dedicated, she needs to feel a type of deep partnership. Only when she feels it can she depend on you emotionally, not just professionally. She needs to know that as an employee I am connected like her to the family mission. This requires something different from me, and spurs me on to accelerated development.

Thus, staff members at BIS are invited to be a part of the BIS family. Family members receive strong and meaningful support, and are given opportunities to grow, create, and contribute to others. In return, they are asked to make BIS a part of them, to accept the vision as their own, and to take personal responsibility for its realization. This arrangement has its advantages and disadvantages for staff members, who expressed some concerns regarding the cost of this commitment for other aspects of their lives:

Beit Issie is not a job for me. I've joined a mission that I am personally a part of and it's a part of me. It's much more than a workplace. A great part of my identity, creativity, energy, skills and love, is put into Beit Issie. This has advantages and disadvantages. I have felt at times that I was in danger of losing my sense of self outside of Beit Issie, and that I have had to fight to protect it.

The work here tends to be very demanding, taking a lot more of one's time and energy than a similar job elsewhere. In the last couple years some of the employees began to set limits, to insist they have other priorities in life – home, family, children – and Beit Issie can't take over everything.

Finally, the following quote from the current chairperson of the board of directors illustrates both the difficulties, and ultimately the satisfactions, of accepting upon oneself the commitment to the BIS vision:

It has sometimes been difficult. I have often felt irritated and frustrated at the burden. Sometimes I wonder if I have taken on too much. But when you make a commitment you just have to live up to it, and you find a way.

Ultimately it brings a lot of satisfaction. I receive more than I give. It's hard to explain. The ability to give, to make a change, to do good for others, benefits me enormously. Beside the basic needs of achievement, of doing well,

of being loved, there's also a great need to feel that I'm not just here for my own self-satisfaction. I and others have a purpose, to have some kind of effect on the world, on my surroundings, on my community. It gives enjoyment, satisfaction, a reason for existence. It's related to being lucky. I have three healthy children. If you are lucky and privileged, it's almost a feeling of obligation. The world is very much out of balance, we have to do what we can to balance it.

The next generation: What it means to be a member of the BIS family

BIS was founded by Issie Shapiro's siblings and children, each of whom has been involved in his or her own way over the years. Over the last two years BIS has made a deliberate effort to enhance the identification of the members of the next generation of the extended family with the BIS family, inviting them to become involved and to contribute in meaningful ways. Interviewees from the next generation described this process and how it has affected them:

Over the last year or two I have become involved in the 4th generation forum, through which my generation is trying to act on its awareness that it's no longer enough to count on our parents doing good, now it's our turn to get involved. It wasn't my idea, but I joined the committee. There are different ways to get involved. We're not able at this stage of our lives to make big donations, but we can become personally involved. This takes initiative and time, for meetings, planning projects. The committee has opened up a way for me to get positively involved, moving us as a group from the awareness of the importance of Beit Issie and our connection with it to the possibility of active ongoing contribution.

The interviewees also referred to the extraordinary effects that this process has had not only for the individuals involved, but for the extended family as a whole:

On the group and family level, it makes us all members of a team, a family cause. Not many other families have such involvement in a family project. At the level of family as team, it brings the family together; it unites. The family together creates synergy, which goes beyond what can be done with individual involvement. It also creates a common ground among family members. Some donate money, others donate time, volunteer, spread the word. Over the course of time, everyone is involved in some way. It unites also those who are not directly involved, just by knowing what BIS is and that they can be proud and take some indirect family credit.

Thoughts about the possibility of imminent succession of the Executive Director.

The current study took place in a critical time in the development of BIS. When the study began in July 2005, only a handful of people were privy to the fact that the Executive Director of 24 years was seriously considering passing on the job to a successor. Interviews for the study with family members and senior staff members were to a certain extent a pilot exploration, to gauge likely reactions within the family and the organization to this eventuality.

In September 2005, just after the interviews for the study had taken place, the board of directors, the senior staff, and the entire staff of BIS were all told in turn that as of January 1, 2006, Naomi Stuchiner would become founding director of Beit Issie Shapiro International, passing on her position as Executive Director of BIS to her professional director, Jean Judes.

The question in the interview, "How do you think Naomi's passing on the job of Executive Director to a successor might influence family involvement and influence?", was phrased so as to leave ambiguous the question of who the successor would be, and to focus responses on the effect of this eventuality on family involvement - a concern in light of the decision to name a non-family member as the successor. Four of the interviewees had prior knowledge of the decision to name Jean Judes as successor (including Jean herself) , five recognized this as an eventual possibility but did not know that the issue of succession was being seriously considered for the near future, and one was not asked the question, so as to avoid premature disclosure to the staff.

There was a consensus among interviewees from the family that if a highly competent potential successor from the ranks of the family were available, this would have a positive impact upon future family involvement. At the same time, no such candidate was identified as being ready for the job of Executive Director at the current point in time.

Given this gap, interviewees from the family and from the staff concurred that the organization's first priority is quality, and that ways would be found to maintain family involvement. This sentiment is best represented by the following quote:

It's hard to point out a specific successor from within the family. I would rather have someone else who is the best rather than compromise to keep it in the family. Family members could fill other senior positions or serve as directors. The Executive Director would need to understand and appreciate the family and its culture, but does not need to be a family member. The family would continue to be involved in networking and fundraising. Beit Issie's interest is the family's interest. What's good for Beit Issie is good for the family. Given

the best person, the family will maintain the same involvement.

Interviewees who knew or surmised that Jean Judes would be the successor emphasized her deep knowledge of and commitment to the family mission:

Jean is Naomi's direct inheritor. She has worked closely with her for years, and she is completely involved in the family and the family concept.

Jean is genuine, caring, and wonderful. She has the institution running through her very fiber. I can't see any negative effects as far as the family is concerned. Jean embodies the family's philosophy and commitment. Clearly, our family involvement will continue. Because of our commitment to the cause and our experience with Jean over many years, our family will always be an integral part of both decision making and implementing.

While the choice was being made, to forgo the possibility that in its next phase BIS would be under the direction of a family member, this did not rule out the possibility that a family member would be ready for the job in the future. Jean Judes herself referred to the possibility, that her tenure as Executive Director would be transitional, until the time when a younger member of the family is ready to take over the position:

In a sense, I feel like I'm holding the torch till one of Naomi's kids is ready. If one of them is competent that's a possibility, but it has to be done very wisely. Deep down I know that this is Naomi's dream – to see her children continue in the work. It's okay for me. It has to be the right timing, the right level of competence, the right process.

Summary of findings

In summary, analysis of the interviews points to a very dynamic picture in which the role of the family, its perception, its attributed meanings, and even its boundaries have changed over the years as BIS has grown and faced developmental challenges.

On the whole, interviewees pointed to important contributions of family involvement, ranging from the resources that made it possible to take risks and to mobilize the support of others, the family's caring and commitment and the added value that the organization derives from them, and the positive effects of family involvement upon the life in the organization. Disadvantages included organizational dependence upon the family, the risks of real or perceived nepotism, and the tensions derived from employing family members.

At the same time, from the content of the interviews and from the different perceptions of interviewees who joined BIS at different times, it was clear that

the issue of family involvement had a dynamic history within the organization. Interviews pointed to organizational developmental crises that had been related to family involvement, and to the explicit and implicit strategies that had been enacted in order to respond positively to these crises and to reach a growth-promoting resolution.

Interviews revealed an entity or identity that has emerged in the organization that reflects a blending of family, organizational, and personal identities: "The BIS family". This identity, and the strategies that seem to have contributed to its emergence, were explored from the perspectives of staff members and members of the next generation.

Finally, interviewees indicated that under the current conditions, the family and the organization were ripe for moving into a next phase, in which the role of Executive Director would be passed on to a member of "the BIS family" who is not from the founding family. Due to an extensive shared history with the successor, deep trust of her professionalism and commitment to the family mission, and to recent efforts to expand the base of extended family involvement, interviewees felt confident that the family would continue its intensive involvement in BIS even when the Executive Director was no longer a family member.

Discussion

As noted in the introduction, the present study reflects a shift from a somewhat apologetic attitude towards BIS's extended family resources to recognition that this "deviance" in the not-for-profit world is precisely BIS's greatest strength and perhaps an important source of learning both for other families, services, and communities. The concluding sections will consolidate some of what can be learned from the study's findings about the unique role played by the founding family in BIS's development. First the findings will be compared to similar findings from the field of family businesses, and then a narrative will be constructed on the basis of the findings to tell the story of BIS's successful coping with an important developmental task. The discussion will conclude by pointing to the next developmental transition that was being negotiated at the time of the study, and to the organizational processes and ethos that made success likely.

Similarities between BIS and Family Businesses

Many of the dynamics revealed in the interviews are recognizable from the literature

on family businesses. For example, many of the advantages of family involvement in BIS described by interviewees echo what Cabrera-Suarez et al¹³ describe as the sources of competitive advantage of a family business:

*One feature of a family firm is the high degree of members' commitment and dedication. This feature is observed in family members, who believe they have a common family responsibility, as well as in other employees, who feel they are a part of the team and display a more enthusiastic attitude than employees of non-family businesses.*¹⁴

Similarly, the disadvantages and tensions concerning family involvement revealed by interviewees are similar to the concerns found by Chua et al¹⁵ in their survey of top executives in Canadian family firms. They note that the top four concerns underlying the issues facing survey respondents were: a) managing family involvement in the business, b) succession, c) relationship with non-family managers, and d) post-succession planning. All of these were of relevance at BIS.

Another theme that emerged, the key role of the extended family in the entrepreneurial development of BIS, also has echoes in the family business literature. Anderson et al¹⁶, in an attempt to bridge between the family business literature and the literature on entrepreneurship, focus on the role of family members in entrepreneurial networks beyond the boundaries of the family firm:

*It seems feasible to argue that appropriate kin outside the formal boundaries of the family firm, working in physically and organizationally distinct loci, may prove excellent virtual members of a family firm. Trust and a sense of belonging are provided by the family context, which also mediates relationship interactions in a positive manner. The benefits that these possible kin network contacts, or virtual members of the family firm, provide to the family firm are likely to be enhanced by their emotional commitment and long-term understanding of the firm.*¹⁷

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- 13. Cabrera-Suarez, K., De Saa-Perez, P., Garcia-Almeida, D. (2001). The succession process from a resource- and knowledge-based view of the family firm. *Family Business Review*, 14, 37-48.
 - 14. Ibid. p.38.
 - 15. Chua, J.H., Chrisman, J.J., and Sharma, P. (2003). Succession and nonsuccession concerns of family firms and agency relationship with nonfamily members. *Family Business Review*, 16, 89-107.
 - 16. Anderson, A.R., Jack, S.L., Dodd, S.D. (2005). The role of family members in entrepreneurial networks: Beyond the boundaries of the family firm. *Family Business Review*, 18, 135-154.
 - 17. Ibid. p.141.

While the above quote refers to the international, even global breadth of the entrepreneurial family network, an additional issue that emerges from the interviews is the family's intergenerational depth: Active involvement in BIS spans four and even five generations. Jaffe and Lane¹⁸ refer to similar families in the world of business as multigenerational family dynasties: Networks of families who are joined as an economic unit, enjoying and multiplying the fruits of the wealth generated long ago by a family entrepreneur. They note that:

Long-standing family dynasties (have a) unique role in the business life and development of the world. By obtaining access to capital with a long-term perspective to provide for succeeding generations, they provide a balancing force for the short-term perspective of financial markets and institutions.¹⁹

Moreover, they note that such family dynasties often operate under a set of deep moral and spiritual values.²⁰

While the extended family that supports BIS does not have anywhere near the kind of capital resources that the families referred to by Jaffe and Lane have, they may have other characteristics attributed to family dynasties, including their spiritual values, their long-term perspective and their positive role in societal development. The achievements of the family in BIS indicate that the concept of dynasty should be explored beyond the realms of capital wealth, in the realms of social entrepreneurship. Surely one could identify other families who over the course of generations, by virtue of their efforts to embody values in social action, remained a cohesive unit that worked from a long-term perspective to promote societal development.

Contributions of the study

While the interviews in the current study elicited the above themes that are reminiscent of issues discussed in the family business literature, the rich qualitative data reflecting the experiences of diverse members of the "BIS family" made it possible to go beyond these themes and to track and make explicit the dynamic, previously implicit developmental stages passed through by BIS. Gerswick et al²¹, in tracing the stages of family business evolution, describe three stages: first generation

18. Jaffe, D.T., Lane, S.H. (2004). Sustaining a family dynasty: Key issues facing complex multigenerational business- and investment-owning families. *Family Business Review*, 17, 81-97.

19. Ibid. p.98.

20. Ibid. p.83.

21. Gerswick, K.E., Lansberg, M., Desjardins, M. & Dunn, B. (1999). "Stages and transitions: Managing change in the family business", *Family Business Review*, 16, 89-107.

entrepreneurship, a second generation "maturing business", to a third generation stage as a "business dynasty". In the present study some of the interviewees described in considerable detail the transition between the first and second stages, while the study was performed at a critical time in the initiation of the transition between the second and third stages. The following section presents a narrative of the transition between the entrepreneurship stage to the maturing enterprise stage, as it emerged from the interviews.

From Entrepreneurship to Maturing Enterprise

BIS was founded by a family in memory of its father and brother, one month after his passing, as a tribute to his legacy and as a means for fulfilling his vision. In 1981 Beit Issie Shapiro was registered as an official non-profit organization in Israel, the mechanism through which to fulfill the dream of a society in Israel in which all people have equal rights and opportunities for a better life. Within a year, Issie Shapiro's daughter, Naomi Stuchiner, a community social worker, became director of the organization. In the organization's early years she was the driving force behind BIS's rapid development and expansion. The organization became an important force for innovation and change in the area of services for children with special needs and their families in Israel, and by 1993 its director was recognized for her extraordinary capacities as a social entrepreneur.²²

As the organization identified unmet needs in the Israeli service system, it initiated and developed new forms of services, generating opportunities for innovation within its auspices. BIS attracted other entrepreneurial professionals who identified with the family's vision, and appreciated the opportunity to work in an organization so aligned with their values. A small but growing core of staff coalesced that developed a sense of family, with their own family members becoming involved in BIS life, including volunteering and working within the organization – alongside members of the family of the Executive Director.

Growth inevitably led to a developmental crisis, as it became necessary for the Executive Director to let go of some of her centrality and control, which had previously been essential ingredients in the organization's success. During this transitional phase, the organization was stretched to its limits. More and more responsibilities were taken on, tasks expanded and staff grew to meet them. With an eye to long term growth, the organization took upon itself major risks in terms of capital building programs that severely stretched available funding. The chairman

22. Rosenfeld, J.M., Schon, D.A. & Sykes, I.J. (1995). Out from under: Lessons from projects for inaptly served children and families. Jerusalem: JDC-Brookdale Institute.

of the board at the time emphasized in his interview that he was worried at the time that the organization was overstretched, as "we started to run short on money we needed for paying salaries". At this point in its history, insecurity ran high and tensions latched on to the family issue. An undercurrent developed that pointed to the existence of two camps, as it were - those in the family, and those outside of the family - with a growing sense of gaps in terms of entitlements and visibility.

It was at this point in time that Jean Judes was hired to be a new professional director. Reflecting the atmosphere at the time, she noted in her interview:

When I first came to the organization people were making bets about how long I would last. I had to earn the trust of the managers that I was not Naomi's puppet. On the other hand, I had to make it clear to them that I was not their puppet or spokesperson. It was essential that I was able to remain differentiated from the agendas of each side, remaining authentic to myself.

Jean Judes, a non-family manager invited to be a senior manager in a family enterprise²³, was between a rock and a hard place. Her active involvement as a self-differentiated mediator at the boundary between the staff and family²⁴, as described in the findings section, required all of her skills and capacities as a community social worker, as well as her total commitment to the family mission. Over time, boundaries were renegotiated, and the split between family and staff subsided, minimizing the impact of family dynamics upon professional decision making. Staff, becoming more secure as the organization moved beyond the developmental crisis and into its next phase as a mature enterprise, let go of grievances and became more focused on the positive contributions of the extended family.

Conclusions

This article signified a first attempt to deliberately and systematically reflect upon and explore the place of the family in BIS's past and present. It explored the phenomenon of family involvement in BIS by combining a literature review with an exploratory qualitative study based on in-depth interviews.

At the time that the present study was being performed, BIS was entering a

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- 23. Chua, J.H., Chrisman, J.J., and Sharma, P. (2003). Succession and nonsuccession concerns of family firms and agency relationship with nonfamily members. *Family Business Review*, 16, 89-107.
 - 24. Riordan, K. (2005). The new leaders: Leadership transitions in family businesses. *Family Systems: A Journal of Natural Systems Thinking in Psychiatry and the Sciences*, 7, 7-27.

developmental process of great significance: transfer of the job of executive director from the member of the founding family who had led the organization since its earliest years, to a professional director from outside the family. The process of succession is being implemented out of the conviction that this step will contribute to the organization's capacity to successfully negotiate its next developmental phase.

For years it was assumed in the family that in order to guarantee the continuity of the family legacy and commitment, the Executive Director's successor would have to be drawn from the ranks of the family. The study revealed that over the past several years, two parallel processes have taken place through which the unthinkable, succession by a non-family member, is currently becoming a reality that has received the broad support of family and staff alike.

The first process took place in the extended family, in which a new "fourth generation" project (or, in the language of the group, the "family network initiative") has been initiated and developed. This project has intensified the involvement of cousins the world over who are currently in their twenties, thirties, and forties. Through their activities in the family network forum in support of the larger family project these family members are taking upon themselves, as both obligation and entitlement, some of the responsibility that their parents took upon themselves before them. The increasing involvement of the next generation decreases significantly the concern that with the passage of time the involvement of the family will wane.

The second process took place in the organization itself among the staff and was described extensively in the findings. Through this process the boundaries of the concept of "family" were extended in the organizational culture so that members of the staff, including the new Executive Director, experienced themselves as belonging to "the Beit Issie Shapiro family", which carried with it a deep identification with the family vision and values. The process of expanding the boundaries of family also took place, though to a lesser extent, among service recipients and their families and among families of donors in Israel and abroad.

These processes, and the current venture into the unknown territory of the next developmental stage as a "business dynasty"²⁵, or in this case perhaps a "social dynasty", demonstrate on the level of the family and the organization the ethos of the family that has long been expressed on the therapeutic and social spheres. Beit Issie Shapiro has proven once again that given an uncompromising commitment to creating a better future, it is possible to act creatively over time within situations which have no apparent solution, and to discover and create unique and previously unseen developmental pathways.

25. See note 21.

The Family Legacy

A Springboard for the Development of Beit Issie Shapiro

Sharon Bacher

So you have a cause: you dedicate yourself to improving the rights, standards and services for persons with developmental disabilities; for people who are by and large unable to fight for themselves. There is a need and you have the passion to resolve it. You are driven by a philosophy that will brook no obstacles: if you will it, it will not be a dream. You need to find the resources, the people and the finance to make it happen.

Where do you start? You start with the people you know - the people who share your values and are likely be inspired by your dreams. For Naomi Stuchiner, this was primarily her family, the crucible where she learned that community involvement was important and that contributing to the welfare and betterment of others was a fulfillment of Jewish commandments.

In developing Beit Issie Shapiro, Naomi and her immediate family were inspired by the legacy of good works left to them by her father, the late Issie Shapiro, in whose memory they established the organization. Issie Shapiro, an attorney and businessman, was a well known community leader in South Africa, having been one of the founders of both the Selwyn Segal Hostel and the Avril Elizabeth Home for persons with developmental disabilities. His passionate involvement in these and other projects inspired his family, who were brought up in the tradition of giving and helping.

Sadly and tragically, Issie Shapiro died early, felled by a heart attack while traveling to the USA to raise funds to build a facility to care for people with developmental disabilities in Israel. When the family decided to take up Issie's mission, it was his youngest daughter, Naomi, a professional community social worker, who took the lead, with the support of her mother Lucie, her brother Max Shapiro, her sister

Esther Boyd and their families.

In seeking support for the project, their first port of call was on their family, which was both large and widely spread across the globe, with branches in the USA, England, Canada, South Africa, Hong Kong and elsewhere. They were eager to help, desiring to establish a memorial to Issie and to contribute a greatly needed resource for the State of Israel. While these members of the family might not come to live in Israel, they were drawn by the opportunity of “tikkun olam”, to serve in correcting the imperfections of our world. Thus it was that the organization became a rallying point for the family’s generous contributions and meaningful involvement in Beit Issie Shapiro. This has been one of the organization’s great strengths and has in turn contributed to the solidarity of the family and the transmission of values of giving, involvement and social action through the generations.

It was no accident that Beit Issie Shapiro’s first fundraising office overseas was set up in New York in the early 80’s because the family had established a substantial business base there. Issie’s sister, Celia and her husband, Willie, had emigrated from South Africa to the USA and identified closely with the aims of the organization.

The Trump family is well known for its philanthropy and its name is associated with a great many projects in the USA as well as in Israel. It was primarily with their backing that Beit Issie Shapiro was able to open its first office in New York and hire a professional staff to create a legal and administrative infrastructure for resource development. From that base the Trumps used their social and business network to recruit many friends and donors. After Celia and Willie passed away, their sons Jules, with his wife Stephanie, and Eddie and the entire Trump’s next generation, took over this responsibility. They remain today the backbone donors and the primary point of influence in the USA, particularly in New York and Florida.

While the Trump family was able to garner support from their wealthy network, efforts were simultaneously made to bring the work of the organization to widen its base of supporters. The American Friends of Beit Issie Shapiro was first registered in 1988 under the name The American Friends of Developmentally Disabled Children in Israel, and later changed its name to the American Friends of Beit Issie Shapiro establishing its National office in Manhattan

Later, when the Trumps relocated to Florida, they used the opportunity to establish a new center of influence, particularly by opening doors to a relationship with the Greater Miami Jewish Federation, which has since become a dependable source of annual support. The American Friends set up an office within the Michael Ann

Russel Community Center, thus providing a base for the development of activities.

Following this, offices were set up in LA, coordinated by Pat and Errol Fine, first cousins who are committed to support Beit Issie Shapiro, and who have continued to play an active and leading role in developing friendships and funding resources there. Nowadays LA not only provides a respectable source of the funding sent from the USA, but it has been responsible for the development of grassroots community education and consciousness raising programs that have made the name of Beit Issie Shapiro a household word in many parts of the country.

Extended family was also the rallying point for the establishment of other offices internationally: in Britain, Canada and South Africa.

A first cousin of Issie, the late Aaron Beare, supported the establishment of Beit Issie Shapiro and remained a major source of encouragement and support until his death. On his passing, the Aaron Beare Foundation continued with annual funding for operating and endowment funds to support Beit Issie Shapiro. The extended Beare family continues to raise money from both South Africa and the United Kingdom. In partnership with the Aaron Beare Foundation, Beit Issie Shapiro was able to launch new innovative services, including the first student training program at Beit Issie Shapiro. And this first step became the forerunner of specialized training programs being set up at universities and tertiary training centers around the country, raising the standards of intervention and service.

The Aaron Beare Foundation has particularly associated itself with subsidizing the treatment of children whose families are unable to pay full fees. This has allowed the organization to live up to its commitment never to turn away any child needing treatment.

In both South Africa and the United Kingdom, the family of the late Aaron Beare, have also played a role in establishing fundraising offices and members of the family have played pivotal roles in recruiting members, developing resources and spreading information about the work of the organization. Other members of the extended Beare family continue to be supportive in the UK and South Africa.

In Canada, Barbara Abrams, a first cousin to the Shapiro's, coordinated all the administrative and fundraising activities for over 20 years until her retirement in 2009. Through her constant and enthusiastic efforts, Beit Issie Shapiro has a sturdy support base, primarily contributing to its Special Education Center for children with Intellectual Disabilities. The Canadians have also made a pioneering contribution

to the development of a special university for young adults with learning and social adjustment difficulties. The Canadian Friends of Beit Issie Shapiro is now led by a new generation of supporters, including some family.

The Trump Family has not merely played important roles in the developing of the American connection, it has financed many innovative and pioneering services that distinguish the organization. Their major contribution in the area of training professionals for this special field, has allowed the organization to move from having a small local impact on changing the way the community relates to people with special needs, nationally. In setting up the Trump International Institute for Developmental Disabilities, they provide opportunities for specialized hands-on training for service providers and skills enrichment programs for professionals. In 1999 they established the prestigious annual Chesed Award – a monetary award recognizing the value of excellence in service delivery and raising the aspirations and pride of professionals working in this field. It was with profound gratitude and recognition for his efforts, that the first Chesed Award was conferred on Willie Trump by Israel's Minister of Health, Mr. Yehoshua Matza, at a poignant ceremony at the Knesset.

Keeping the family involved in Beit Issie Shapiro has been a mission and a constant challenge. While the contributions of family members have always been appreciated, the nature and extent of family involvement has often been a source of concern and controversy.

Never one to sweep problems under the carpet, Naomi Stuchiner typically decided to confront the dilemmas and motivated the enactment of policy decisions on the issue. She made no pretense of the fact that she saw the organization as a living memorial to her father and was interested in maintaining a strong family involvement at every level of the organization's function. From the organization's point of view, it was clear that they depended on the family for the backbone of support and that it was this that helped the organization weather the great financial challenges it has faced over the years. However, Naomi's interest in maintaining the family's involvement was additionally motivated by the opportunity to transmit the family legacy of caring and compassion through the generations. There is no doubt that by rallying around a common endeavor, they have strengthened their family bonds.

The conflicts the organization and family faced have been described in greater detail elsewhere in this book¹. One of the more difficult questions that had to be

1. See chapter10: Exploration of Issues Related to Founding Family Involvement and Executive Director Succession in Beit Issie Shapiro's 25th Year.

confronted was the issue of employing members of the family in the organization. Apart from the difficulty this posed for the family itself with its potential for generating conflict and dissonance, the main concern of the public was for nepotism. In an effort to mitigate this, a principle was established that a family member might only be eligible for employment if he or she possessed demonstrably superior training and skills than other applicants. On the other hand, it was also agreed that family members should not per se be excluded from employment. A summary of the key positions and contributions made by family members over the years, can be seen in the attached graphic².

As the parent generation of the family passes on, it is exciting to see that the years of identification with Beit Issie Shapiro are bearing fruit in the continuing involvement of the next generations of children and grandchildren. The extended Shapiro family continues to play key roles in representing and supporting the organization's work. In a way this mission has become a symbolic magnet that reinforces family connections and provides them with a stake in the building of a humane and caring community in Israel. Their sons and daughters are actively involved on committees in many parts of the world. The grandchildren and great-grandchildren celebrate their birthdays, bar-mitzvahs and bat-mitzvahs with the children in the educational centers and feel at home in the corridors of the building. In 2006, the grandchildren from all over the world dedicated a therapy room to honor their grandparents, Tillie and Solly Lee; Celia and Willie Trump; Fay and Effie Fine; Issie and Lucie Shapiro; and Razelle and Montie Goldstein.

Family is integral to all Beit Issie Shapiro does and stands for. Though it draws its strength from the support and steadfast dedication of the family of Issie Shapiro, the value of 'family' has also been a driving force in shaping the direction of the organization's development.

At the time Beit Issie Shapiro was established, most children with intellectual disabilities were placed in institutions. This was heartbreakingly for many families, but there was little choice since there were no good community-based educational and treatment facilities, and most services provided by the government were based on institutional care. The Stuchiner-Shapiro family wanted above all to afford families the right to choose whether to place their child in an institution or to raise him or her at home. And this could only become feasible to the extent that essential support services would be made available to them within their home community.

2. See a family tree on page 132.

This goal directed the development of a continuum of family therapeutic and empowerment services for the whole family (including grandparents and siblings) and of programs to teach parents the special skills needed for coping with a chronically ill child at home and effectively advocate for better services and entitlements. As a result of this policy, while the organization cooperates with the medical and welfare system, its uniqueness lies in having pioneered a range of services for families in the community, thereby making it possible for thousands of children with special needs to be raised at home and enjoy a normal family life.

The concept of extended family at Beit Issie Shapiro is inclusive rather than exclusive, and it has been expanded over the years to include all those who are identified with the organization. Staff members are also encouraged to think of themselves as members of the extended Issie Shapiro family. Their children are invited to special events and annual summer camps, and in 2000 the Trump Family established the Trump Chesed Education Fund which contributes towards the higher education and training of the children of staff members. Nowadays many children of staff members play a role as volunteers or even as the next generation of professionals.

One may see from this article that the notion of 'family' has been a central one in the life cycle of Beit Issie Shapiro. The role of the founding family has been pivotal, but it has also been inclusive, welcoming the wider family of Issie Shapiro and encouraging them to make whatever contribution they can. Some are on committees, others have been donors. They provide funding and both fundraise and 'friend-raise' for the organization. Others provide professional services, and still others have joined the staff team and are making unique contributions of their own.

Following Naomi Stuchiner's retirement from the active management of the organization, the challenge remains to keep the family of Issie Shapiro meaningfully involved. How will the organization strive to maintain their excitement, their identification and sense of ownership of the organization? What roles will the grandchildren and great-grandchildren of Issie Shapiro play, and how will the organization relate to their interests, desires and needs to carry the family legacy into the future? How will Naomi herself find meaningful expression in the organization, as it moves on to a new era without her playing a central role?

The Shapiro-Stuchiner family has made an incredible contribution to the people of Israel – not only through the services Beit Issie Shapiro provides, but also through the values of compassion, caring, involvement and – above all – hope, that they

inspire in others. However, it is possible that their greatest strength comes from the generosity of spirit with which they welcome all in the embrace of their family in striving to realize a vision of a better world.

VI

From the Past Towards the Future

The Changes and Developments that Took Place in the State of Israel in the Area of Developmental Disabilities, and the Role of Beit Issie Shapiro

Professor Arie Rimmerman¹

Introduction

In this brief chapter I have taken upon myself a sizable task, to provide an overview of the changes and developments that have taken place in our country in the area of developmental disabilities, and following that to point out the role that Beit Issie Shapiro has played in these developments. Over the years I have been involved in various ways in Beit Issie's activities and since in my opinion Beit Issie has played a leading role in developing high-quality services in this area, I gladly took this task upon myself.

If we look with an historical perspective upon policy in the area of disability in Israel, we see the influence of both local and external forces. In general, the internal forces were stronger than the external forces, but not always. I will discuss this later when I identify the different developmental periods.

I will start with an anecdote that highlights the importance of the external influence. Very few people know that the stimulus for the 1969 Law for Care of the Retarded was the first international conference on Intellectual Disabilities that was held in Israel at that time. Josef Burg, the Minister of Welfare at the time, was encouraged to demonstrate that Israel has a relevant legislation related to people

1. Professor Arie (Arik) Rimmerman, Richard Crossman Professor of Social Welfare & Social Planning, Social Welfare and Health Sciences, University of Haifa; Distinguished Professor at the Newhouse School of Public Communication, Syracuse University. This chapter is based on a lecture given at the seminar "Closing Circles: 30 Years of Social Change" which was held on 26th January 2011, to mark the retirement of Naomi Stuchiner from her executive roles at Beit Issie Shapiro.

with intellectual disabilities. Burg was receptive and brought the proposed law to the Israeli Knesset (Parliament). The legislation is still the core law today regardless of the changes that have been made.

Historical Trends in the Area of Disabilities in Israel

There is a significant difference between Israel and other western countries with respect to policy toward people with disabilities. In the United States and in Western European countries, policy was crystallized through dialog and/or conflict with organizations of people with disabilities². In Israel, in contrast, policies were set primarily by government, which controlled their content, the legislative processes, and their implementation. Only recently has government endeavoured to involve disability advocacy groups in policy-making. However, their role remains passive and limited, mainly responding to government initiations.

There are three important legislative periods related to people with disabilities. The first period began with the establishment of the State and continued into the 1980's. Legislation during this period was based on the medical model. The government enacted three laws providing benefits and rehabilitation services for army veterans with disabilities, work related disabilities and disabled populations generally. Compensation decisions were governed by medical committees. The underlying conceptualization was, basically, socio-medical, providing differential benefits and services according to severity of disability and an assessment of needs.

By the end of the 1980's there was a shift in the way in which services for people with disabilities were conceptualized. The language context changed from socio-medical and institutional care to a preference for the principle of 'normalization' with a view to community integration. The significance of this was that there was an upsurge of interest in community-based services and provision in the least restrictive environment. These took a long time to implement. For example, the Special Education Law was passed in 1988, but only began to be implemented in 1995. Implementation in Israel lagged in comparison to practices in the Western World.

The heart of the policy and legislation from 1995 onwards is the Equal Rights for Persons with Disabilities Law (1998). This law is grounded in principles of human rights, and assures the right of every person with disability to equality, dignity, and active participation in society with regard to all aspects of life. The legislation is

2. Rimmerman, A. & Herr, S. S. (2004). A. The power of the powerless: A study of the 2000's disability strike in Israel. *Journal of Disability Policy Studies*, 15(1), 12–18.

very progressive and similar to the Americans with Disabilities Act in the US as well as other western countries. However, its implementation faces numerous obstacles, primarily budgetary.

Thus, we can identify two different approaches that exist side by side: The socio-medical approach, that focuses on providing selective and individual benefits to people with disabilities on the basis of disability and entitlement tests; and the rights approach, that is based on the principle of equal rights of all people. Most of our laws are socio-medical laws, the new legislation promotes rights, accessibility, and prevention of discrimination. This is precisely the split in which we find ourselves. Although we value disability rights, we are still providing services that are aligned with the socio-medical model. I would define this as one of our central problems today.

Trends in the Area of Developmental Disabilities in Israel

In this section I will refer specifically to trends in the field of developmental disabilities. It is commonly thought that in the early years of the State there were no services for this population, but this is not really the case. I recently came upon early documents from the Levzeller institutional care facility and found that already in the early 50's there were solid professional practices. And according to early documentation provided by Benjamin Cohen, one of the leading founders of Akim - (the National Association for the Habilitation of Children and Adults with Intellectual Disabilities) - there were innovative programs here before and after 1948. However, these were local and sporadic initiatives by individuals rather than organisations.

The years between 1948 and 1961 were years of State building. The emphasis was on solving immediate social problems, and the easiest solution was to establish institutions for out-of-home placement. We need to remember that back in the 50's people with intellectual disabilities were considered to be a human tragedy. Most of the relevant social work literature in the 1950's dealt with the question of how to reduce parental stress by offering reasonable out-of-home placement for offspring with intellectual disabilities. The service infrastructure at that time was basic. We only began developing our special education system which was established by 1961. During these years Akim was the frontrunner in offering innovative employment and leisure programs, and this organization had a major influence on the government's policies. Anyone looking at Akim today should realize that it made its greatest contributions during the early years of the State.

If we move on to the 60's and 70's we can identify the development of a professional

community significantly influenced by international knowledge. International experts were brought to Israel to recommend educational and employment programs. Interestingly, the 1968 international conference served as a catalyst to legislation and other innovative programs.

From 1986 to 1997 we see an accelerated development of both institutions and community based programs. Since I was a consultant during this time to Ora Namir, who served as Minister of Labour and Welfare, I can tell you that this was a period of extraordinary activity, one in which the government developed and expanded the resources and services for people with intellectual disabilities. Beit Issie Shapiro – at the time a small local initiative in Raanana that offered innovative and outstanding early intervention services to children with disabilities and their families - was a classic example of the kind of entrepreneurial initiative that arose during this period.

This was very important, yet there was no prioritization of community over institutions. Each developed alongside the other and this trend of developing institutions alongside community services continued even until the early years of the new century. In its continuing development of institutions Israel was an exception among western countries, most of which moved away from institutionalization as a way of relating to persons with developmental disabilities. In contrast, Beit Issie Shapiro was, from the beginning, committed to community services. The first time that I came into contact with the community approach was through Beit Issie Shapiro.

Since 1998 the government has changed its approach toward people with intellectual disabilities and now pursues a policy of "affirmative action", beginning at birth or childhood and providing increased resources for this population. The policy aims to promote high quality services tailored to their needs, degree of intellectual disability and age, and to encourage the development of independence, personal choice and fulfilment of individual potential. An additional change has been a commitment to promoting interventions whose effectiveness has been proven (evidence-based). I see this accelerating in the last decade, and especially in the last few years.

Since the 1980's there has been impressive progress in the quality of professional practice. This began with the initiation of Master programs in rehabilitation social work at Bar Ilan and Haifa Universities. Today Israeli universities can be proud of their extensive academic and research infrastructure, with many specialized programs offered for BA and MA degrees.

Alongside these developments one can see a growing development of advocacy organizations. The most significant catalyst for the movement was probably the 1999 strike by people with disabilities themselves (in the United States similar

developments took place already in the 1970's). Unfortunately, as there is little independent funding for such organizations, their effectiveness as advocates for change is too often compromised by a financial dependence on income generated from providing services, many of which are funded by national or municipal government.

The Role of Beit Issie Shapiro

Beit Issie's foremost legacy is one of human rights. In order to begin thinking about the role of Beit Issie Shapiro in these developments I took a look at Beit Issie Shapiro's profile as appeared in the organization's official statement. Perhaps the most important sentence appears first: "Every person has the right to live with dignity and in accordance with his full abilities". This was stated many years ago, long before the acceptance of the Equal Rights for Persons with Disabilities Law (1998).

Furthermore we see is that "Beit Issie Shapiro acts to change the quality of the lives of people with disabilities and their families, by developing educational-therapeutic services, furthering social change, promoting awareness in the community, research, development, and training." There are three very important terms here: Quality of life, family and community.

The core message about Beit Issie Shapiro that stands out is the drive to bring about change. Not everyone wants to make changes. Many prefer to stay with yesterday's world. A number of years ago I took part in a discussion that takes place every year around the question: What needs to be Beit Issie Shapiro's agenda? On the table was the question "Maybe we were mistaken, maybe we need to operate differently?" In other words, there is a constant striving for the most effective ways to bring about change.

The symbol they have see p. to encapsulate their mission – the "Hamsa"³ – an oriental 5-fingered charm - is very interesting because it encompasses all that the organization does and it speaks for itself. It highlights research and training, but also family. Family and community have a very conspicuous place. I did an analysis of Beit Issie Shapiro on the basis of its internet site and I can tell you that it was the first organization in Israel in the field of developmental disabilities that had worked actively to create partnerships for change on a local level. No one else was doing this in the early 1980's.

3. See p. 43.

Beit Issie has been a pioneer in providing quality services in early childhood. Developing early childhood services for children with developmental disabilities, when there was no funding at all for this purpose, was nothing short of revolutionary. In 1981 it was impossible to even talk about early childhood. The only concern at that time was the abandonment of children with Down Syndrome in hospitals.

Beit Issie Shapiro is one of the few organizations that I know, which manage knowledge. It was pre-occupied with knowledge management long before others came to use the term to brand themselves. I remember the library, which at the time seemed so strange to me. I would tell them, "Beit Issie Shapiro is not a university". But as an organization committed to transmitting knowledge to its clients, it took care to provide them with an up-to-date library. This same drive has since developed beyond the library, to the books that Beit Issie publishes, as well as to the international conferences that it hosts. All of these testify to an ethos at whose heart is the constant pursuit of new knowledge, wherever it may originate, that can contribute to the quality of lives of people with developmental disabilities and their families.

Beit Issie has become an expert in operating special programs for training, supervising, and disseminating knowledge on a national level. I could give a long list. Each time I look at the Special University, at the workshops produced in the Trump Institute, at the groups of organizations of people with disabilities, and at discussions that took place there, I am reminded of Beit Issie's striving to build innovative knowledge and share it with others. They do this in a great variety of ways.

And one of the most impressive things about Beit Issie Shapiro is the broad consensus that it enjoys. I think that to be in this field for 30 years, and to be accepted by everyone - the government, state agencies, parents, families, disability activists and academia - is one of the organization's great accomplishments.

Challenges for the Future

If I were to be asked now to present in a nutshell what the State of Israel needs to do in the area of intellectual disability, I would say the following:

First of all, it must reduce the number of people living in institutions. There's no escaping it, we don't look good. Our numbers are quite poor in comparison to other Western countries.

The second thing we need to do is to increase the budgets designated for community services, alongside a gradual and adjusted reduction of allotments for

out-of-home placement. The whole Western world today implements the ‘waiver’ model, a model that gives families the power to choose and purchase services in the community that meet their needs. The waiver model is extremely important because it enables different people to receive different services, and I am glad that last year the Government held very serious discussions on this matter with an international expert.

A third thing that needs to be done is a national survey and mapping of services. We have no true map. We became aware of this in the last war. It is in a time of the wars that we discovered how little we know about the demography of our people with developmental disabilities, where and under what conditions they live, what services they need and where these are provided, and how we can assure them of the continuation of these vital services in a time of war and its ensuing chaos. When you want to plan services you first of all look for numbers, and these, meanwhile, are lacking.

Finally, this coming June (2011), the Government is convening an international committee of experts to discuss the standards for what need to be met to enable people with intellectual disabilities to live with dignity in the community. The government deserves praise for moving in this direction of benchmarking, and for its openness to learning from the best practices in other countries.

Learning from the Past, Shaping the Future

Jean Judes¹

A thirtieth anniversary is a potent time in the life-cycle of an organization. It is a time to look at the strengths that we have developed and capitalize upon them for the future.

We have good reason to be proud of our accomplishments in direct service to our clients, as well as of our impact on the national and international realms. As we look to the future, it is clear to us that in order to keep living up to our mission, we must continue to create new knowledge as we re-create ourselves.

The key to our success that has made us a leader in the field of disabilities is our ability to adjust our services to the constantly changing and often chaotic environment and to new realities as they develop. This ability has allowed us to find opportunities in the challenges and to act upon them. Our most marked success has been in joining forces with several key non-profit organizations and working together towards social change. The synergy developed through these alliances is critical for success and growth.

On the basis of our experience and the knowledge that we have developed over these years, we have developed a strategy for the future that incorporates a systemic understanding of the spheres of life that determine the quality of life of our clients and their families. The first of these spheres relates to our own organization and includes direct service to individuals and families. The second sphere goes beyond our walls and includes the nature of community values and attitudes, as well as governmental policies, entitlements and restrictions. The third sphere is global. It is the sphere where knowledge on disabilities is being developed and shared between countries, both by universities and service organizations, as well as disability leaders.

In all these spheres we emphasize the need in the future for systematic knowledge development through research, training and knowledge management.

The first sphere encompasses our organization. Foremost among the challenges facing us as an organization is to maintain our commitment to our values and mission by developing new and innovative ways to serve the changing needs of our clients, while maintaining organizational stability and sustainability. This dual commitment

1. Jean Judes, M.S.W., Executive Director, Beit Issie Shapiro.

is not a luxury. It is a necessity. As one can see in previous chapters of this book, the environment in which we operate as an organization has changed dramatically over the past thirty years – in no small part due to our initiatives. There are now many other high quality organizations offering services that are up to the standards that we have developed and promoted along these thirty years. As an example, our school for children with intellectual disabilities, which once was so exceptional that it attracted parents to bring their children from distant cities, is now one of six excellent such frameworks in the center of the country alone. However, there is currently a shortage of quality schools for children with cerebral palsy who are unable to be mainstreamed into regular schools and we have chosen to organize and move to meet this need. In this example, and in others, we are challenged to be sensitive to shifting needs and directions, and proactive in developing a dynamic process for change.

There are many areas that demand attention in the future. There are challenges stemming from the development of modern technology which can increase the independence and quality of life of people with disabilities and the development of specific services to meet hitherto unmet needs, as in the case of services for Arab children with autism.

In the national sphere, we are actively involved in community organization and development. We are active in kindergartens and in the school system to promote attitude change towards people with disabilities. Also, we are leaders in the area of inclusive leisure opportunities. Our community work includes developing advocacy partnerships for much needed legislative and policy changes.

We are increasingly serving as a resource to other organizations who are interested in learning from our expertise in order to promote their mission. For example, the organization for people with the rare syndrome “Family Disautonomia” has used our support and consultation. The Schneider Children’s Medical Center of Israel has received support from us on how to use the snoezelen to lower anxiety in children with cystic fibrosis. We have many such examples, and we see our mentoring role as an important endeavor in the future.

In the international sphere, we have been busy over the past years developing the connections that Naomi Stuchiner established with leading academics and professionals abroad. We have become active participants in the international community of practitioners and scholars through international conferences, workshops, joint programs and research with colleagues from abroad. For example, we have undertaken groundbreaking research with the University of Toronto and University of Brisbane, Australia on family quality of life (FQL). Together with them we developed a tool to measure those variables that promote or hinder the quality of life of families with a child with special needs. This tool has been translated into 22 different languages and its impact has been truly international. Another example

is the research on the use of the snoezelen to lower anxiety in the dental clinic. This research is being replicated by the University of Southern California and Dr Michele Shapiro from Beit Issie Shapiro will be a consultant to their research.

There is no doubt that in engaging in these networks we are also contributing positively to the image of Israel abroad. Our global outreach is a major direction for future development.

The systemic view of our organization directs us to continue advancing in these three spheres. In the organization's interior sphere, we are in the process of developing a systematic foundation for knowledge development and management that will be able to make the most of the amazing knowledge and experience of our staff and allow us to leverage broader social change. In our next phase we plan to upgrade our practice by making knowledge development and management an organizational priority and explicit goal. This will include giving our staff the support necessary to develop their practice into models, updating and upgrading our library, and developing new functions on our internet site and other social media.

In the second sphere of future activity, we have found that the key to making an impact on our society lies in simultaneously educating the community on tolerance and acceptance, and creating broadly based collaborations to promote equal opportunities through legislation and policy. We will continue to advance partnerships and collaborations with other organizations. We have learned about the importance of developing teams that work jointly with voluntary groups, local community organizations and indigenous professionals. We are committed to engaging local people in our learning processes, enabling them to represent the interests and needs of their community as they develop the capacity to take increasingly greater responsibility for developing and implementing excellent practice.

Another exciting partnership we wish to expand in the future is the research partnership with people with disabilities. Inclusive and participatory research has made it possible for people with disabilities to voice their perspectives and participate in the conduct of research that has an impact upon academic researchers, decision makers, and professional practitioners. We hope to strengthen this initiative and create a national and international network on participatory research. This will ensure that we allow our clients and their families to be true colleagues and partners in social change. Over the next few years, we hope to strengthen the voice of marginalized groups who have difficulty being heard. Participatory research is just one such avenue.

Finally, we are committed to continuing to act in the international sphere. There are areas of great growth and development of knowledge abroad which are of critical value to the disabilities community in Israel. An important goal of our international collaborations will be to import this expertise, adapt and implement it within our own

treatment settings and disseminate it to the broader service system in Israel. On the other hand, at this stage of our development it is now clear that not only do we need to import knowledge, but that we have much to contribute to the world. Overseas communities are turning to us and asking us to export our expertise. Our "Controlled Multisensory Simulation" Programs (Snoezelen), hydrotherapy programs and our accessible park have brought international recognition. Our staff members are invited abroad to teach as well as to lecture in conferences, and our research is published in leading international journals. Our international collaborations strengthen our organization and increase our ability to offer cutting-edge services.

Three Major Challenges for the Future

1. Commitment to Knowledge Development and Transfer

Beit Issie Shapiro has continuously been a consumer of relevant knowledge generated by research and "translated" into high level services for our clients. Today, most researchers agree that the successful movement of new knowledge into clinical practice or policy-making environments is an interactive process that requires dialogue between researchers, clinicians, policy makers and clients. This interactive engagement is the 'name of the game', and we want to develop it as a paradigm for the future.

For our organization to continue to transform and develop we must encourage learning, both individual and collective, as well as change conceptual paradigms. If knowledge development is to impact upon attitudes, behaviors and practices, it must be within the context of working in a learning culture, continually enhancing our capabilities to create and nurture expansive patterns of thinking, set collective aspirations free, and create a milieu in which people are continually learning to see the whole together!

2. Serving Children in a Multi-Cultural Society

In our work with the ultra-orthodox community as well as in our Sindian Center in the Arab town of Kalansuwa, we have become aware of the necessity of building culturally sensitive services. The issues faced by people with disabilities are especially difficult for populations that are not part of the dominant culture. Language barriers, negative stereotypes and attitudes all contribute to and exacerbate the experience and disadvantage of disability. The training of future health and social care professionals to work in minority communities is a main commitment for Beit Issie.

We have entered a process of collaborative work with local professionals to clarify and discuss our own cultural beliefs and develop a framework for working cross-culturally. We begin with a critical examination of our own beliefs and attitudes in order to recognize that we are all shaped by a culture

that gives us our identity and informs our values. This sense of who we are affects, both consciously and unconsciously, our interactions with others, as individuals, as professionals, and as an organization committed to service. We have come to an understanding of the importance and value of celebrating diversity in our society and our world. Given this background we will seek in the coming years to build on this insight in practical and meaningful directions.

3. The Emotional Needs of People with Disabilities

An important issue that has emerged from our work with people with disabilities and their families is an awareness of the failure of services in Israel to identify and relate to the emotional needs of people with disabilities. There is a need for greater recognition of the emotional needs of children and adults with learning disabilities, in addition to their behavioral and mental health needs, and to develop more appropriate and effective interventions. People with intellectual disabilities are at increased risk of developing mental health problems in the future (prevalence rates are around 30% higher for young people with intellectual disabilities as compared to young people without intellectual disabilities). Young people with learning disabilities also have a higher prevalence of emotional and behavioral problems than those without. Recognition of the emotional needs of children and adults includes the areas of dual diagnosis and infant emotional development.

Conclusion

In conclusion, in order to achieve our goals we need to remain closely connected to the needs of our clients and to our environment. We need to continue to be responsive, to revisit our strategies and to have the courage to change directions. We need to remember that we are not here just to be service providers. We are here to be on the cutting edge of innovations that contribute to the quality of life of people with disabilities and their families. We must hone our capacity for self-criticism and curiosity as we actively reflect on the world around us, continually clarifying and focusing our actions and decisions. Above all we must maintain a courageous commitment to our mission.

When I look at the future of Beit Issie Shapiro I see an organization committed to, and capable of continuously improving the quality of life of people with disabilities through its active involvement in Israeli society and in the wider global community.

The *Mishna* tells us that "... at twenty years of age we are still finding our place in the world but at thirty we reach our strength (*Ethics of the Fathers* 5:24). We must now apply our strength, energy and commitment to tackle those issues that will make a better society for people with disabilities and their families".

Epilogue¹

November 2011

Naomi Stuchiner

A month ago my dear friend and mentor, Gerald Blackman, passed away. The truth is that my earliest memories as a child include Gerald, who was my brother Max's best friend for over 65 years. When I was a little girl, Gerald would come to play with Max, and Esther and I were the little sisters not to be related to...

I never dreamt then or later as I grew, that I would actually develop an independent relationship with Gerald. This started while I was establishing Beit Issie Shapiro – and Gerald became my teacher in financial management, which I desperately needed to learn in order to succeed in directing the rapidly growing organization. From the very beginning, when Gerald first heard my dreams, he identified me as an entrepreneur, though at the time I didn't know what he was referring to, and only in retrospect have I come to understand. He knew my strengths as well as my weaknesses. He understood and valued my free spirit. He knew that I could not and should not be put into a box.

Gerald moved from being my mentor, to becoming a board member, and later the head of the audit committee not only of Beit Issie Shapiro, but also of our International Friends of Beit Issie Shapiro. In both organizations he established the finest and most professional financial systems, worthy of any large and excellent organization. He was also a most valued member of our Financial Committee.

When I retired from my executive roles at Beit Issie Shapiro in 2006, Jean Judes, the executive director who took over from me, quickly realized that she too had an excellent teacher and mentor in Gerald, who continued to support Jean, the Board and the staff of Beit Issie Shapiro.

Gerald was my friend – a real friend who was able to listen more than most people, act from wisdom and experience, intervene when necessary and move aside when

1. My thanks to Professor Victor Friedman, whose review of the Hebrew book and subsequent correspondence helped me formulate this reflection.

this was the best thing to do. He challenged me, cared about me, and on numerous occasions stepped in to mediate some of the more challenging issues. He always cajoled me towards more; gently smiling in recognition of my entrepreneurial nature.

As this book goes off to print, I think a lot about how important Gerald was for me. When I set out on this adventure, I could not have imagined all that has happened to me. So many stories come to mind – too many to relate in one book! I made my Dad's vision for social change, my own, and this gave me an idea of where I wanted to go. What I would have to do to get there was a total mystery. For thirty years I took one step at a time, buoyed at each challenge by my deep conviction that what I was doing was correct and that I should follow my instincts. I learned that the big vision guides one's direction, but getting there divides into hundreds of smaller visions that only surface with time. Some of these came from the initiatives of others – staff, parents, children, volunteers, donors, and colleagues – whose energy and enthusiasm inspired me, and together we pioneered new paths to advance our shared mission. What it took from me was to encourage them to go for it, and to create the organizational context that would support them. As Gerald was for me, I tried to be for them.

When I look at most of the staff at BIS who contributed to revolutions in their fields, I note that none of them started as social entrepreneurs, but each was given an opportunity to take their ideas and fly with them, contributing in their own ways to the new milieu. Tuvia, who had to overcome the tremendous complexities of being the executive director's husband to make his enormous impact on the field of hydrotherapy; Michele, who came in as an occupational therapist, a clinician, became a leading force of change in her field the field of multi-sensory intervention; Lili, who began as a psychologist in the early development program, developed her own vision for innovation and excellence as director of therapeutic day care programs; Nira, who was a remedial sports instructor, developed the Sports and Therapy department; Bonnie, a clinical social worker and family therapist, has been leading the dual diagnosis initiative into a real force in Israel. The examples go on and on.

Beit Issie Shapiro has consistently moved beyond what was imagined possible, and it is this unleashing of human potential that lies at the heart of the organizational DNA. Part of what has made this possible is that BIS itself has been in a constant process of moving into the next level (a process that has been very demanding and often even frightening for the staff and other stakeholders). People who join the BIS family can develop because the organization is constantly calling upon them to innovate and create, and nurturing their untapped potential.

I believe that every person has a Divine spark that is lit up in the right environment. I have seen that spark ignite again and again in the people who have joined us in our mission. Once the fire is burning, once people know that they really have the backing to engage in work that inspires them, that contributes meaningfully, and that challenges them to grow, they become social entrepreneurs, and they take this with them wherever they go. Now that I have retired from my leading position at BIS, other people have taken up the baton under the leadership of Jean and the organization continues to provide them with opportunities to realize their dreams.

As I look ahead, I understand that I have a new vision. Imagine what our society and world would look like if it were filled with organizations in which every organizational participant was supported to be a social entrepreneur in his realm - organizations that make space for their creativity and nurture their Divine spark. I wonder where this vision will lead and marvel at the unexpected pathways that will be opened up by the initiatives of people I do not yet know, but hope to meet in the years to come.

About the Authors

Naomi Stuchiner is the Founder, former Executive Director and current President of Beit Issie Shapiro. Through her work in Beit Issie Shapiro, over the past 30 years, she has been instrumental in leading a change in the field of developmental disabilities in Israel. Naomi is recognized as an expert in social entrepreneurship and resource development. She has won a number of awards, including: the ‘Henrietta Szold Award for Social Work’ in 1989, the ‘Prime Minister’s Shield of Child Award’ in 1999, the ‘Outstanding Director of the Voluntary and Nonprofit Sector’ award in 2004, and the ‘Lifetime Achievement Award’ from the Institute of Certified Accountants in Israel in 2008.

Israel Sykes is a social entrepreneur, organizational consultant, writer and action researcher who specializes in production of knowledge and processes that contribute to societal healing. During his career in Israel, he has made a significant impact in a variety of fields, including mental health, disabilities, welfare, education, and Jewish Renewal.

Sharon Bacher combines her training as a social worker with experience in fundraising at Beit Issie Shapiro. She was responsible for Beit Issie Shapiro’s English documentation and developed a rich database of information about the organization over 22 years, affording her a wide perspective with which to conceptualize its development.