Debra H. Zand

Katherine J. Pierce

Editors

Resilience in Deaf Children

Adaptation Through Emerging Adulthood

Foreword by Irene W. Leigh

Springer

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Editors
Debra H. Zand
Missouri Institute of Mental Health
5400 Arsenal
St. Louis, MO 63139
USA
debbie.zand@mimh.edu

Katherine J. Pierce
Department of Psychiatry
Washington University School of Medicine
660 South Euclid Ave.
St. Louis, MO 63110
USA
piercek@psychiatry.wustl.edu

Printed on acid-free paper

For Hannah & Abrahm – our child guides to understanding the resilience pathway

Foreword

Throughout much of history, deaf people have been misunderstood and misrepresented by societies that magnify their inabilities and try to change these to abilities that will allow for their seamless merging into the hearing population. For deaf people, this is a frustrating odyssey that often results in an inadequate sense of belonging within the auditory environment swirling around them. Communicating and relating to others in ways that do not match the surrounding society's expectations of typical communication usually results in negative responses and distancing from others. It is no wonder that hearing parents are weighted down with concern and worry when they discover that their infants/toddlers are deaf.

Refreshingly, the past few decades have witnessed an astounding explosion of publications that explore the ways in which deaf people have forged ahead with their lives. These publications have accelerated the shift away from the perception of deaf people as a subgroup at risk for maladaptive lives if they don't "overcome their disability" to focus on their ability to survive and manage their lives competently, all things being equal. This relatively recent focus on strengths, healthy functioning, and positive psychology has been a long time coming.

The authors contributing to this book, *Resilience in Deaf Children: Adaptation Through Emerging Adulthood*, have continued this trend away from the historically negative framework by focusing on the concept of resilience as a positive attribute that each one of us has the capacity to possess. Resilience is a concept with multiple definitions, as has been made abundantly clear throughout the chapters. Most typically, resilience has been defined in terms of the ability to withstand adversity. Other approaches to this construct rely on a dynamic paradigm that incorporates developmental and transactional processes between oneself and the various environmental influences that mold and reshape the ability to confront the various vagaries that life offers.

Reading through the chapters, I could not help but reflect on my own life story and how my own resilience evolved. As it should for many deaf people, the critical points made by the contributing authors resonated with me. I was not identified as deaf until the age of 2. I was blessed by parents who provided warmth, affection, and access to communication and language after overcoming a week's worth of mourning for the loss of their idealized hearing child. Utilizing the steadfast support of a therapist experienced in working with young deaf children, my parents

spent untold hours ensuring a language-rich environment for me, even though both had to work full time. They made it comfortable and "normal" for me to be deaf. They affirmed my desire to be with deaf friends as well as hearing peers. When my academic and social abilities as a deaf girl who spoke differently were questioned, the principal of my elementary school fought against entrenched opinions that I as a deaf student could not succeed in challenging post-elementary educational environments. These dynamic ecological influences, and more, conspired to form within me a resilient, solid, and coherent sense of self capable of facing indifference, doubt, opposition, and outright discrimination as well as the joys of life.

My experiences and the perceptions of the various authors in this book highlight the importance of considering not only individual characteristics but also the ecological systems that surround the individual. Edna Simon Levine's (1981) seminal book, *The Ecology of Early Deafness*, was one of the early significant texts to bring attention to the critical importance of the interactive role of self and environment in enhancing the development of deaf persons. She noted how an unaccommodating, noninclusive environment could result in individual deficiencies, even when the deaf child had significant potential. The importance of reforming the environment to enhance communication access and appropriate development was a constant theme for her.

How accommodating environments could be created has been highlighted by a parade of books that followed Dr. Levine's. For example, *Deaf in America: Voices from a Culture* (Padden & Humphries, 1988) taught the public how culturally Deaf people created an approach to life that was functional and full of human connections, enhanced by visual ways of communicating. This approach is grounded in an environment that accommodated their communication and social needs in ways that were normal for them. Creating a new center of normality that can stand alongside the normality of people who hear was a critical contribution to the notion that deaf people are capable of full lives and dealing with risks in their own ways just like everyone else. This new center reinforced the expectation that deaf children could be well-adjusted and resilient given appropriate access to the world around them.

With that expectation in mind, books such as *The Deaf Child in the Family and at School* (Spencer, Erting, & Marschark, 2000) began to look at the nature of interactions between the deaf child and the family/community/school systems as well as the philosophies that guide these systems. The book you are holding in your hands has taken this scrutiny of accommodating environments and theoretical frameworks one step further. Its authors have proposed various system constellations that contribute positively to the deaf child's evolving resilience. A number of them focus on Urie Bronfenbrenner's (e.g., 2005) theoretical paradigm that encompasses the critical bidirectional influences of distant systems such as culture and government and more immediate systems such as schools or the medical establishment, for example, as these directly and indirectly influence the deaf child via family and neighborhood systems, and vice versa. How these systems are shaped can have powerful influences on resilience and sense of self as the child transitions to adolescence and young adulthood. This is a dynamic process that requires some goodness of fit between individual characteristics and the various systems in order

to enhance the potential for resilience. Although the complexities of this process are daunting, the power to mold the child demands that it be carefully attended to. In this book, the authors successfully break down the complexities into components that readers can try to apply in their own situations.

Again and again in this book, the contributing authors refer to the family system as a centerpoint that serves (as it did for me) to pave the way to the incredible possibilities of being a resilient deaf person. Based on research documentation, strongly emphasized throughout the book, the nature of attachment, relationships, and family communication – whether via a signed or spoken language – are key components for the development of resilient deaf children. Given professional support to encourage them to work on strong family relationships and communication, parents are more likely to be intuitive in meeting their child's needs. Using this as a foundation, the authors provide practical suggestions that will enhance the ways multiple systems (family, community, neighborhood, school, workplace, and so on) can facilitate social support and resilience, thereby enhancing the deaf child's capacities for relatedness, competence, and self-determination.

This book is a welcome addition to the burgeoning literature that focuses on the strengths and capabilities of deaf people for managing their lives. It provides a refreshing look into how these positive attributes can be developed throughout the early phases of the life course. It provides us with theoretical paradigms that help us conceptualize how resilience can be fostered in any deaf child, whatever the internal attributes and external circumstances may be. And it provides hope that society can and will recognize that deaf people can and do make significant contributions to the fascinating diversity of human lives.

Gallaudet University   Irene W. Leigh, Ph.D.
Washington, DC, USA

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About the Editors

Dr. Zand is a clinical psychologist and Research Associate Professor at the University of Missouri–Columbia, Medical School, Department of Psychiatry. For the past 14 years, her work has focused on child and adolescent mental health and resilience. During this time, she has been responsible for writing, designing, and directing multiple federally funded longitudinal grants. Her most recent project focuses on fostering bonding between medically fragile, developmentally disabled young children and their caregivers. Dr. Zand has taught both graduate and undergraduate courses in research methods and mental health policy, mentored graduate students and junior faculty, published in peer-reviewed journals, and presented findings in local, state, and national forums. Recently, she was accepted into the American Psychological Association's Leadership Institute for Women in Psychology.

Dr. Kathy Pierce, a clinical psychologist at Washington University's School of Medicine – Department of Psychiatry, specializes in novel interventions for persons with treatment-resistant depression. Over the past 6 years, Dr. Pierce has worked on both industry and federally funded clinical trials, serving as a supervisor, psychometrician, treater, statistician, co-author, and/or grant writer. Prior to working at Washington University, Dr. Pierce was the Evaluation Director for a nonprofit agency providing care for AIDs patients, and co-led Missouri's "Deaf Mental Health PAH," a statewide deaf mental health advocacy group.

About the Contributors

Elizabeth B. Adams, M.A., received her M.A. in psychology from Gallaudet University and is currently pursuing a Ph.D. in clinical psychology from Gallaudet University. She is a co-editor of the *Gallaudet Chronicle of Psychology*, a student-run journal that truly reflects the working, living, and learning that takes place at Gallaudet and within the Deaf community.

Shirin D. Antia, Ph.D., is a full professor at the University of Arizona in the Department of Disability and Psychoeducational Studies. She was born and educated in India and has considerable international and intercultural experiences in special education. Her research interests are in the area of peer interaction, social integration, and best practices in inclusion of Deaf and Hard of Hearing children. She has authored numerous research articles and chapters on these topics. Most recently, she was the principal investigator of a research grant to examine the social and academic status and progress of deaf and hard of hearing students in public schools over a 5-year period.

Patrick J. Brice, Ph.D., received his Ph.D. in clinical and developmental psychology in 1983 and has been at Gallaudet University since that year. He first completed a postdoctoral fellowship in psychology at Gallaudet in 1983, taught in the Department of Counseling from 1984 until 1995, and since 1995 has been a professor in the Department of Psychology. He has been the Clinical Psychology Ph.D. Program Director since 2001. In addition to his teaching at Gallaudet, Dr. Brice has studied various aspects of development in deaf children, including social cognition, self-regulation and executive functions, social–emotional development, and parent–child attachment. He is a reviewer for The *Journal of Deaf Studies and Deaf Education* and the *Journal of the American Orthopsychiatric Association* and also serves as a grant reviewer for various funding agencies. Dr. Brice has also been a consulting psychologist to the Lab School of Washington, St. Elizabeth's Hospital, The National Health Care Foundation for the Deaf, and the Family Service Foundation in Maryland. He maintains an independent practice of psychology in Maryland and District of Columbia He specializes in parent–child attachment, adult attachment, social and cognitive development of deaf children, psychological assessment, and individual psychotherapy.

Cindi Cassady, Ph.D., a clinical psychologist in private practice in San Diego, CA, has worked with deaf and hard of hearing individuals and their families for the past 20 years. She is co-clinical director of mental health services at Deaf Community Services, as well as clinical supervisor at the Bridgman Group Home, which serves emotionally and behaviorally disturbed youth, ages 12–18. Dr. Cassady also specializes in working with perpetrators and victims of domestic violence and is certified by the Department of Adult Probation to facilitate a 52-week domestic violence group for deaf male perpetrators.

Rachel Gali Cinamon, Ph.D., is an associate Professor in the Department of Counseling and Special Education, School of Education, Tel Aviv University and is also Head of the special program for career counseling for young adults, Tel Aviv University.

Susan Daniels, OBE is the chief executive of the National Deaf Children's Society, UK.

Johannes Fellinger, M.D., is a neuropsychiatrist, pediatric neurologist and Head of the Neurological Institute for Language and Senses – Health Center for the Deaf of the Hospital of St. John of God in Linz, Austria.

Lorraine Green, Ph.D., is a lecturer in social work at the University of Manchester. Her main research interests include gender and child welfare, abuse, and children in vulnerable settings or circumstances.

Peter C. Hauser, Ph.D., is an Associate Professor of Research and Teacher Education at the National Technical Institute for the Deaf at Rochester Institute of Technology, Rochester, New York where he is the Director of the Deaf Studies Laboratory (DSL). His laboratory follows three strands of inquiry that focus on the (a) separate effects of sign language fluency and different levels of hearing on cognition, including attention, executive functions, memory, and reading processes; (b) psychosocial development of deaf students and the impact of audism on education; and (c) development of sign language assessment instruments. He is also the Director of the Neurocognitive Foundations of Vision for Language and Communication Research Initiative at the National Science Foundation Science of Learning Center on Visual Language and Visual Learning at Gallaudet University, Washington, DC.

Daniel Holzinger, Ph.D., is a clinical linguist and Head of the Centre for Language and Communication of the Neurological Institute for Language and Senses – Hospital of St. John of God in Linz, Austria.

Susan Kashubeck-West, Ph.D., is a licensed psychologist and Associate Professor at the University of Missouri–St. Louis. Dr. Kashubeck-West's primary research interests fall into two main areas: body image and eating disorders, and multicultural issues (broadly defined). She is interested in issues related to sexual orientation, race/ethnicity, and gender, primarily as they relate to psychological well-being.

Erin A. Kennedy, Ph.D., is a Developmental Psychologist and Assistant Professor in the Department of Psychology at Lock Haven University in Lock Haven, PA. She

has conducted research on bullying in adolescence, socio-emotional adjustment of children with siblings who have been diagnosed with serious illnesses, self-esteem and academic motivation in college students with learning disabilities, and issues related to gender-typed behavior in childhood.

Lynne Sanford Koester, Ph.D., is a Developmental Psychologist who specializes in infant development and parent–infant interactions, particularly with children who are deaf. She worked previously at the Max-Planck Institute for Psychiatry in Munich, Germany, and at Gallaudet University in Washington, DC. Her current position is at The University of Montana–Missoula, where she is a Professor in the Department of Psychology.

Janet E. Kuebli, Ph.D., is a Developmental Psychologist and Associate Professor at Saint Louis University where she also directs the Undergraduate Studies Program in psychology. Her research interests include emotion development, including the role of family discourse in emotion socialization; children's health/safety socialization; and the psychology of parenting.

Jason Listman, M.S., is currently a faculty member in the Department of American Sign Language and Interpreting Education at the National Technical Institution of the Deaf. Prior to becoming an ASL instructor, he worked at the Deaf Studies Lab (DSL) from 2004 to 2009, working closely with Dr. Peter Hauser in areas such as linguistics, cognition, and psychosocial factors relating to the deaf experience. Mr. Listman hopes to begin his doctoral program in Education in 2012, with his primary research interest being resilience in deaf adolescents.

John Luckner, Ed.D., is a professor and the coordinator of the Deaf Education teacher preparation program in the School of Special Education and the Director of Research for the Bresnahan/Halstead Center at the University of Northern Colorado. Dr. Luckner was a classroom teacher of students who are deaf or hard of hearing for 9 years. His primary research interests include literacy, social–emotional development, teacher preparation, and the provision of appropriate services for students who are deaf or hard of hearing and their families.

Pamela Luft, Ph.D., is an Associate Professor of Special Education at Kent State University in Ohio and the Director of the Deaf Education program. She received her M.Ed. in Deaf Education from McDaniel College, her M.S. in Technology for Persons with Disabilities from the Johns Hopkins University, and her Ph.D. from University of Illinois at Urbana–Champaign in Special Education. She worked in public, special day and residential schools as a teacher, behavior specialist, career coordinator, and program administrator before getting her doctorate. Her research and grant projects have focused on transition services and rehabilitation services for the deaf. She has published on issues related to transition, technology employment of persons with disabilities, special education policy, and instructional practices.

Jennifer Lukomski, Ph.D., is an Associate Professor at Rochester Institute of Technology School Psychology Program. She teaches for RIT as well as consults with Greater Rochester school districts regarding school programming for deaf and

hard of hearing youth. She also has a clinical practice. Her research focus includes social–emotional issues related to deaf and hard of hearing learners.

Linda Risser Lytle, Ph.D., is an associate professor and director of the Summers Only School Counseling Program in the Department of Counseling at Gallaudet University. She also maintains a private practice, working with deaf and hard of hearing individuals and their families. Dr. Lytle is interested in issues surrounding the development of deaf female identity. She is currently intrigued by the richness and complexity of using narrative inquiry as a research tool and how the use of stories influences both teller and listener.

Nicole McCray, Ph.D., is a recent graduate of the Developmental Psychology graduate program at The University of Montana–Missoula. Her research focuses on parent–infant interactions and interventions with at-risk populations.

Jill Meyer, M.S., is a licensed clinical professional counselor conducting research at the Missouri Institute of Mental Health in St. Louis, MO. She is also a doctoral candidate at the University of Missouri–St. Louis. Her background is in rehabilitation counseling and counseling education. Ms. Meyer's primary research areas are disability issues (including deaf studies) as they relate to rehabilitation and well-being.

Rinat Michael is a doctoral student in the Department of Counseling and Special Education, School of Education, Tel Aviv University.

Tova Most, Ph.D., is an associate Professor, and Head of the Department of Counseling and Special Education, School of Education, Tel Aviv University.

Gina A. Oliva, Ph.D., was a professor in the Department of Physical Education and Recreation at Gallaudet University until her retirement in 2009. She continues to be active professionally through publications, presentations, and consultations.

Gina's first book, *Alone in the Mainstream: A Deaf Woman Remembers Public School* (Gallaudet University Press) was published in 2004. Her current research and writing interests include deaf–hearing friendships and alliances, the development of social capital in summer and weekend programs, and the social needs of youth with cochlear implants.

Joan M. Ostrove, Ph.D., is an associate professor of psychology at Macalester College in St Paul, Minnesota. Her research concerns the connections between individual psychology and social structure. She is currently working on projects related to the ways in which social class background shapes people's experiences in higher education and about how people build alliances across differences related to social identity. Her work on alliances is focused on relations between Deaf and hearing people, and between people of color and white people. She is currently on leave from Macalester and is a student in the Interpreter Preparation Program at Ohlone College in Fremont, CA.

Susanne Reed, Ph.D., is a researcher at the University of Arizona. She taught deaf and hard of hearing students in public and center-based programs, preschool

through high school for 18 years. Her research interests are in the area of best practices for inclusion of Deaf and Hard of Hearing students. Dr. Reed is the author or co-author of several peer-reviewed articles and a book entitled, "*Itinerant Teachers of Students Who are Deaf and Hard of Hearing: Their Beliefs and Practices for Developing Literacy*."

Katherine D. Rogers, M.Res., is a NIHR (National Institutes of Health Research) doctoral fellow working within the Social Research with Deaf People group at the University of Manchester. Her main research interests include the mental well-being of deaf children and mental health assessment in Sign Language.

Linda R. Shaw, Ph.D., is a Professor and Department Head, in the Department of Disability and Psychoeducational Studies at the University of Arizona. Prior to her current position, Dr. Shaw was Director of the Rehabilitation Counseling Program at the University of Florida. A licensed mental health counselor, Dr. Shaw's research focuses on disability, human rights, rehabilitation ethics, and professional issues in rehabilitation counseling. Dr. Shaw has published and presented widely on issues related to disability-related job discrimination and the correlates of professional ethical behavior.

Martha A. Sheridan, Ph.D., is a professor of social work at Gallaudet University where she teaches courses in human behavior and the social environment, social work practice, and field instruction. She has worked as a clinical social worker in school, community mental health, and private practice settings, and as an administrator, educator, consultant, and advocate. Her publications include *Inner lives of deaf children: Interviews and analysis* (2001) and *Deaf adolescents: Inner lives and lifeworld development* (2008).

Nicole Renick Thomson, Ph.D., is a Developmental Psychologist and Research Assistant Professor of Psychiatry at the University of Missouri St. Louis's Missouri Institute of Mental Health in St. Louis, MO. Her research interests include the etiology and prevention of youth alcohol use, socio-emotional development in early childhood, parenting, moral development and gender identity. Her recent publications have appeared in *Sex Roles, Pediatrics, and Journal of Adolescence*.

Christine Yoshinaga-Itano, Ph.D., is a Professor in the Department of Speech, Language and Hearing Sciences at the University of Colorado, Boulder. Professor Yoshinaga-Itano has certification as both an educator of the deaf and an audiologist and has conducted research on the development of young children with hearing loss and their families since the 1970s. She has focused on the interrelationship between language and communication skills, cognition and social–emotional development.

Alys Young, Ph.D., is a Professor of Social Work Education and Research at the University of Manchester and director of SORD (Social Research with Deaf People). She has published extensively on families with deaf children and service development and evaluation.

Part I
Introduction

Chapter 1
Critical Issues in the Application of Resilience Frameworks to the Experiences of Deaf Children and Young People

Alys Young, Katherine D. Rogers, Lorraine Green, and Susan Daniels

Abstract In this chapter, the authors take a critical look at the application of resilience-based frameworks to the experience of deaf children/young people. They begin by discussing three key issues: the implications of defining deafness as risk or adversity, in the face of which one is required to be resilient; the significance of the socially constructed nature of outcome-oriented definitions of resilience in the context of deaf children; and the extent to which the individualization of resilience may obscure significant aspects of deaf children's experience in society. They go on to look in detail at how factors and processes associated with resilience may be difficult or differently achieved in the case of deaf children arguing that research is not yet adequate to investigate from d/Deaf people's perspective how they might define what it is to be resilient. The chapter reviews the small amount of specific research that does exist in relation to resilience and deaf children, but questions whether a concern with resilience is not just ultimately a rebranding of the evidence and insights of the much broader corpus of research concerning deaf children's optimum development.

Resilience is an enticing concept. It focuses attention on what it is that enables people to bounce back despite numerous setbacks; it forces us to understand how and why children might succeed despite adversity; and it offers the hope that early disadvantages, harm or pain do not determine a negative trajectory for children's futures. Thus to understand resilience – why one may have it and one may not – is potentially to understand what might make a positive difference, what might enable success, and how to engender greater coping resources in all. Certainly, the study of resilience has flourished in many fields and resilience-building interventions are increasingly common. However, the application of resilience-based frameworks to the lives of deaf children and young people is new. Very little research that directly addresses resilience has been carried out in this context, although as will become

A. Young (✉)
Social Research with Deaf People Programme, School of Nursing, Midwifery and Social Work
University of Manchester, Manchester, UK
e-mail: alys.young@manchester.ac.uk

apparent from this book, there is much that could be said to be related to resilience, or which implicitly addresses resilience.

In 2007, the authors were commissioned by the National Deaf Children's Society (NDCS) in the UK to write a comprehensive literature review on deaf children and resilience (Young, Green, & Rogers, 2008). NDCS, the largest organization in the UK representing deaf children and their families, was considering a program of work aimed at maximizing deaf children's resilience. Understanding the available literature was an important first step. However, as we began the work, it became apparent that the application of resilience-based frameworks to the lives of deaf children and young people was not without its problems. At a theoretical level, we began both to interrogate the validity of the concept in this particular context and to investigate how the experiences of deaf children and young people might bring something new to mainstream understandings of resilience. In this chapter, we will outline some of the theoretical challenges this confluence of resilience and deafness raises for us as a contribution to critical debate and critical practice. As a postscript to this chapter, the original commissioner of the literature review will offer her reflections on the issues we have raised.

The Problems of Deafness as "Risk" in the Face of Which One Is Resilient

In general terms, resilience is used to refer to the factors, processes, and mechanisms that in the face of significant risk, trauma, adversity, stress, or disadvantage, nonetheless, appear to work to enable an individual, family, or community to survive, thrive, and be successful (however those outcomes may be defined). Differing constituencies of interest will approach resilience with differing emphases. Resilience may be seen as the counterweight to psychopathology (Rutter, 2000), as a generally required adaptability to significant challenges (Singer & Powers, 1993), as inherent traits or acquired skills (Bartelt, 1994; Rigsby, 1994), as specific to particular processes in particular contexts (Cohler, 1987; Jacelon, 1997; Ungar, 2004), or as synonymous with desirable outcomes (Jackson & Martin, 1998; Olsson, Bond, Burns, Vella-Brodrick, & Sawyer, 2003). However, regardless of such differences, one thing remains constant, namely, the definition of something as risk/adversity/stress/trauma/disadvantage, in the light of which we recognize resilience. Rutter (2000) makes a telling point in suggesting that one of the methodological problems with much research on resilience is that it does not clearly enough define or justify that source risk. Has the adverse experience or disadvantage really been proven to be such, so that consequent identified features and processes of resilience are valid? In this respect, we must ask ourselves how and why deafness may be regarded as risk in the face of which a child and/or their family may be resilient and what the implications might be of that definition for how we define and promote resilience.

We do know that deafness in childhood (particularly early childhood and severe to profound deafness) is linked developmentally with a greater likelihood of a host of

less than optimal outcomes, be they in the domains of literacy (Conrad, 1979), mental health (Hindley, 1997; Hindley, Hill, McGigan, & Kitson, 1994; Hindley & Kitson, 2000; Sinkkonen, 1998), social and cognitive functioning (Greenberg & Kusche, 1989; Marschark, 1993), educational achievement (Powers & Gregory, 1998), vulnerability to abuse (Obinna, 2005; Sullivan, Brookhouser, & Scanlon, 2000), or future employment and socioeconomic opportunity (Dye & Kyle, 2000). However, this is not the same as saying deafness itself is a risk factor for such outcomes. Rather deafness in a range of familial, social, and institutional contexts may interact with variables and processes that make its potential negative effects more likely.

A classic example in this respect is that of child protection. Deafness does not necessarily render deaf children more vulnerable to abuse, but care and educational circumstances where there are fewer opportunities to be able to communicate effectively with adults to discuss protection and/or disclose abuse might make deaf children more likely targets for abusers (Kennedy, 1989; Sullivan, Vernon, & Scanlon, 1987). These types of interactions between trait and environmental contexts are what Rutter (2000) describes as "proximal risk mechanisms" (p. 653). The key distinction here is that deafness may be a risk indicator, but is not of itself a risk mechanism. Nonetheless, some studies persist in failing to make that distinction. For example, Kramer, Kapteyn, and Houtgast (2006) in a study of occupational performance conclude that "…hearing impairment should be considered as a risk factor for fatigue and mental distress which may lead to sick leave" (p. 510). Yet their own study addresses how it is interaction with features of the workplace that may create disadvantageous experiences for deaf workers, not the fact that they have a hearing loss per se.

The second issue in thinking about deafness as risk in the face of which one wishes to develop resilience questions the nature of the relationship between deafness and disadvantage from a sociopolitical perspective. If one accepts the notion of Deafness as a defining feature of cultural-linguistic identity (Lane, Hoffmeister, & Behan, 1996; Padden & Humphries, 1988), rather than an audiological impairment, then the nature of the risk associated with it concerns the failure to enable deaf children to have developmental opportunities to realize that identity. Paradoxically, from this perspective, resilience could be defined in terms of outcome as the achievement of a signing Deaf identity and membership in the Deaf community, despite the range of hearing-oriented discourses and institutionalized preferences (oral education, cochlear implantation, medical model understanding of deafness as impairment) that might work against such achievement through one's childhood (Ladd, 2003). In other words, resilience could be defined as resistance to conformity or to imposed normative expectations, a little-explored approach in the mainstream literature (Grover, 2002; McAdam-Crisp, 2006 are rare exceptions).

This particular paradox became literally transparent when two of the authors first discussed the original literature review project in British Sign Language (BSL). One used a sign for resilience akin to that of "protection" with the direction of the movement of the sign toward the body. For her, a primary meaning of resilience was the opposite of risk – what was it that acted to protect the individual against adverse consequences of stressful, traumatic, or disadvantageous life experiences? It drew attention to the individualized and to some extent internalized nature of psychosocial

features such as repertoires of coping skills and positive cognitions. The other took up the discussion and used a sign akin to that of "resistance," with an outwards movement of a closed fist away from the body and upwards. For her, resilience was that which enabled one to fight back and continue to dismiss those features of a world that might seek to diminish all of which one was capable. It drew attention to the influence of societal attitudes and structures which could discriminate and disadvantage.

Indeed in BSL, there is no consistently recognized sign for "resilience" (yet) and in the course of the project we remained alert to those used by others and what they might betray about how resilience was understood in relation to deafness and its conceptualization (or not) as risk, disadvantage, and vulnerability. In ASL too, there is yet to be a conventional sign but one often used emphasizes the notion of bounce-backability.

The third issue in considering the relationship between deafness as risk/disadvantage/trauma and resilience concerns how comfortable or not we might feel about defining deafness as an undesirable trait to be overcome or survived (Woolfe & Young, 2006). Within such a framework, resilience becomes evidenced by having done so. Yet as the disability movement has successfully critiqued, the discourse of overcoming one's disability as evidenced through achievement renders any kind of achievement exceptional, thus reinforcing the normative low expectations that society might otherwise have. It diminishes what may be of value in simply being who one is capable of being (rather than having to be a heroic figure who overcomes despite the odds).

Our point here is that resilience, if used to indicate a remarkable or exceptional trajectory for deaf children, runs the risk, paradoxically, of reinforcing low expectations for the majority and making success unexpected rather than normal. Also, as has been pointed out in another context, to align resilience with the definition of success is potentially to open the door to withdrawal of support for individuals no longer deemed to need it if regarded as resilient (Rigsby, 1994).

The Problem of Resilience as Outcome in the Context of Deaf Children

Commonly in the mainstream literature, predefined *outcome* definitions of resilience dominate analyses of process (how someone becomes resilient) without questioning the definition of the resilient outcome in the first place. A study of resilient care leavers (i.e., foster care children) (Jackson & Martin, 1998) is a case in point, but this is a methodological problem that spans a great many studies (e.g., Hampson, Rahman, Brown, Taylor, & Donaldson, 1998). In the Jackson and Martin study (1998), resilience is defined by the display of exceptional academic success against the odds. Consequently, research subjects are classified into a successful or unsuccessful group against this criterion, and then differences between the two groups are investigated. What differentiates the groups against the agreed outcome provides the definition of what constitutes resilience.

The problem is the a priori definition of what counts as a resilient outcome constrains the nature of the analysis. Rather two-dimensional connections are sought

between variables that might differ between the two groups and the outcome. Also, as Rutter (2000) argues, a variable is hardly a mechanism (it does not explain the pathway to an outcome) and while the presence of enabling factors may be taken as connected with resilient outcomes, this is absolutely not the same as saying their absence accounts for why a resilient outcome is not achieved.

Furthermore, we may want to question the definition of resilience used in the first place. It has been well argued (McAdam-Crisp, 2006; Serafica, 1997; Ungar, 2004) that one of the problems of much resilience literature is that it fails to acknowledge the socially and culturally constructed nature of the outcome definitions of resilience that are used (e.g., academic success as normative social good). Grover (2002, 2005), for example, argues children's attempts at survival and being resilient with dignity under difficult conditions are often interpreted as evidence of psychopathology or conduct disorder, particularly if they involve the breaking of legal rules. Yet their behavior may be clear evidence of resilience, if we were to positively value its manifestations.

For example, children protesting against institutionalized care conditions by running away or completely rejecting the value of education, rules, or social conformity could be seen as resilient, but according to different outcomes and criteria from those normally evoked (Cirillo, 2000; Green, 1998; Morgan, 1998). A similar point could be made in relation to deaf children in oral schools where signing was banned and children punished for its use, yet they still learned to sign from their deaf peers and still valued it as essential to their personhood.

In relation to deaf children, therefore, a pertinent question becomes what counts as a resilient outcome and what are the assumptions and values that underpin its definition and by whom? To ask such a question is not necessarily to deny resilience as an entity, but is to draw attention to the fact that outcomes perceived as evidence of resilience are themselves socially and culturally constructed. Unfortunately, the few research studies specifically related to resilience in deaf children/young people have taken a less critical approach to the problem of a priori definitions of resilience based on outcome markers.

Applying a strict definition of resilience in deafness research (i.e., one that specifically utilizes resilience theory and models), we were only able to locate two publications (Charlson, Bird, & Strong, 1999; Rogers, Muir, & Evenson, 2003) that empirically applied resilience as a framework for their investigations. One was, however, founded on a data set previously collected, Charlson, Strong, and Gold (1992) and we further identified one publication that argues for resilience as evidential from deaf adults' narratives of childhood (Steinberg, 2000), which we discuss later.[1]

Charlson et al. (1999) use a rather simple outcomes-derived approach to investigating resilience in deaf young people. That is to say, they identify (through others' nomination) deaf young people regarded as "outstandingly successful" (taken from

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[1] It should be noted that resilience in the context of deafness has acquired some currency in the field of sign linguistics where it is a term used to denote those features of language that appear in deaf children's communication systems whether or not they have been exposed to a conventional language model (Goldin-Meadow, 2003, Chap. 16). These linguistic sources are not regarded as relevant for this purpose.

Charlson et al., 1992) then investigate a subsample of three of them (through case study) to identify those factors associated with success, which are then presumed to be synonymous with resilience.

To be fair, the authors do not themselves define a successful outcome for deaf children, they allow those who nominate relevant deaf young people to set that definition. It is, however, noticeable that in so doing, the nominators predominantly reinforce the notion of resilience being associated with exceptional achievement (e.g., in education and sports), rather than resilience being associated with the successful acquisition of those skills and abilities that enable one successfully to respond to stressful or adverse life events *as a matter of course*. This alternative, nonexceptional approach to what is resilience has been neatly summed up elsewhere as "ordinary magic" (Masten, 2001).

Rogers et al. (2003), while also taking a predefined outcomes approach to the investigation of resilience, go one step further and begin to consider what might be an appropriately defined "successful" outcome *specifically* for young Deaf people. In their case study of three Deaf young people they:

> "…define resilience as the exemplary ability to bridge the Deaf and hearing worlds both socially (i.e., through leadership roles in the Deaf community) and in terms of work success (i.e., working a combined total of 40 hours weekly in one or more hearing settings), despite the risk and challenges that may be associated with audiologic and linguistic differences" (p. 223).

Although, in this study, the social and political construction of what counts as a resilient outcome is acknowledged in its definition being so precise and context specific, there is little justification for why that particular definition is seized upon. Within the highly contested field of deafness, where multiple paradigms (medical, social, and cultural) compete to define what it is to be d/Deaf, one cannot imagine that Rogers et al.'s (2003) definition of a resilient outcome is one that would be shared by proponents of all communication methodologies, nor indeed by all culturally Deaf insiders.

Our point here is fundamentally that in the deafness field there is still much basic research work to be done on exploring *what is resilience (including a resilient outcome) as understood and constructed by deaf children and adults themselves*, even before we seek to understand those factors and processes that may promote, sustain, or indeed reduce it. That said, this small corpus of work does offer some insight into processes, traits, and mechanisms seen from d/Deaf perspectives that the authors associate with the resilient outcomes they have predefined. We return to these issues later.

The Problem of the Individualization of Resilience in the Context of Deaf Children

A further potential problem in applying resilience-based frameworks to understanding the situation of deaf children concerns what we are terming the individualization of resilience. A great deal of mainstream literature concerning resilience, particularly