

# Self-injurious behaviour in people with intellectual disabilities

Richards, C.; Symons, F.

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## **Self-injurious behaviour in people with intellectual disabilities**

Tremendous advances have been made in the past four decades in our understanding of self-injurious behaviour (SIB) among individuals with intellectual disabilities (ID). Despite such progress, there are myriad complexities making SIB a deeply disturbing clinical challenge and continuing scientific puzzle. Our understanding of the pathway or pathways to its development are relatively limited and remain more theoretical than empirical. We have little direct evidence that we can predict with certainty who is more or less 'at risk' among vulnerable populations to guide early intervention or prevention efforts. Teasing apart behavioural mechanisms has been the cornerstone of our scientific understanding of maintenance, but cases and subgroups still present considerable clinical challenges, for example those with automatically maintained SIB. The question of syndrome-specific SIB and risk factors remains important as we continue to resolve and refine genotype-phenotype relations that may provide insight into specific vs. shared features of SIB co-morbid with genetic ID syndromes. For all of the issues, the evidence is ambiguous and still relatively 'thin'.

A central aim for the present special issue was to encourage papers in all of these areas, spanning disciplinary boundaries and drawing on data collected from basic science through to clinical intervention. We hope that this inter-disciplinary special issue will accelerate the pace of our collective understanding, by cross-pollinating ideas with high relevance for models and mechanisms of SIB. The excellent research presented in this special issue includes data derived from pre-clinical (i.e., animal) models of SIB, cross-sectional and longitudinal epidemiological studies targeting risk markers for SIB and fine-grained experimental behavioural science elucidating and modelling relevant contingencies. We still have many unanswered questions, but the papers in this special issue significantly progress our understanding and have the potential to improve specificity and efficacy in SIB interventions for people with ID.

Whilst collating and editing this special issue, we were greatly saddened to learn that Professor Stephen Schroeder had passed away. Steve was a pioneer in SIB research, leading the discipline in innovative approaches to quantify the behavioural and biological contributions to SIB. He was also a great teacher, mentor and friend to many in the field. The remainder of this editorial is dedicated to reflections from Steve's students, mentees, colleagues and friends, as a tribute to his lasting scientific and personal influence.

### **Professor David Felce**

I first met Stephen Schroeder at a conference organised by Sharon Landesman at Lake Wilderness in Washington State in the early 1980s. He and Bill Maclean gave a paper entitled "If it isn't one thing, it's another: Experimental analysis of covariation in behavior management data of severe behavior disturbances". He was a big, quietly spoken man, who reminded me of John Wayne.

Shortly after, as the co-editor of *Research in Developmental Disabilities* with Johnny Matson, he invited me to join the editorial board. I accepted but told him that I had not reviewed papers before and would appreciate feedback on the first few that I did. He was tremendously helpful.

I remember too meeting him and his wife, Carolyn, when he was visiting the Hester Adrian Research Centre. Chris Kiernan took us all for a meal in a great restaurant in Didsbury. It was a lovely evening.

Steve combined behavior analytic skills, with a wider view of the possible causation of challenging behaviour, and a knowledge of psychopharmacology. Who better to ask for advice when a group of us at the Welsh Centre for Learning Disabilities and the Hester Adrian research Centre conducted an open randomised trial of withdrawal of anti-psychotic medication. He said that there would be some unexpected reactions, but was positive and encouraging.

### **Dr. Deborah A. Napolitano**

According to Merriam-Webster.com, in Hawaiian the word *kahuna* is a reference to a priest or shaman, someone who is at the top of their field. I often thought of Steve as our big Kahuna. Someone who was at the top of his field, his game, but there was something else so special about him. Steve taught me how to mentor others. How to build teams. How to support others so that they can be the best professional they can be. In a world where people often behave in ways to further their own careers, Steve taught me that one of the best ways to further one's own career is to be inclusive. That is, Steve believed that the best way to lead was to include others and to promote others because you are only as good as the folks working with and for you. You get further when all the people with whom you work achieve their best and are successful.

One of the things I am most proud is that Steve considered me one of his "girls". That I am proud of being considered one of his "girls" is kind of ironic because I used to get mad at my father when he referred to the women with whom he worked as "his girls". Steve's girls are a group of amazing women who were among his last students and/or mentees. It may sound corny, but he pushed us and supported us so that we would be the best professionals and people we could be. He was so proud of everything we do. He enjoyed watching our careers. Steve hated Facebook, but apparently had an account so he could keep track of us, our families, and our professional achievements. I always knew that I could talk to Steve when I needed advice. That is, Steve was there when I wasn't sure which path to take. Much of the (hopefully) sage advice I give to those I now mentor and teach is directly related to or analogous to advice Steve has given me for the past 20+ years. I will forever be grateful for his caring, mentorship, and support. He is deeply missed.

### **Professor Maria Valdovinos**

Steve Schroeder was a pioneer, respected scholar, visionary leader, and wonderful mentor. The best advice I received from him was advice he had once been given himself, "Know your reinforcers." Steve was a source of reinforcement for so many. Generous with his time and expertise, Steve would never hesitate to consult on an issue, facilitate connections with others, pass along relevant literature, and work on projects (even though he'd "retired" in 2001). Under his tutelage, an appreciation for the intersection of biology and behavior grew for so many of us in the field. I, like many others, will always remember Steve's kindness, compassion, honesty, perspective, humor, support, karma talks, and most of all friendship.

### **Dr. William E. MacLean**

I met Steve Schroeder at the Gatlinburg Conference in 1977. I was a first year graduate student surrounded by the most prolific researchers in the field of intellectual disability. I was torn between continuing my undergraduate research interest in problem solving by children with mild intellectual disability or shifting to the study of stereotyped behavior. A few conversations with Steve decided the outcome and defined my career interest in repetitive

behaviors among people with intellectual disability. His experience and knowledge regarding stereotypy as well as self-injurious behavior was staggering. Steve lived a life of empirical research devoted primarily to problem behavior although there were occasional forays into other applied issues such as over-activity, lead exposure, and automobile driving to name just a few. The strength of his research emerged from an emphasis on strong empirical methods, use of innovative measurement approaches, and a focus on brain-behavior relationships. For me, Steve was a mentor, friend, and professional role model. What impressed me most about Steve was his ability to tell stories while laughing hysterically. He really enjoyed a good laugh.

### **Professor David M. Richman**

My first encounter with Stephen R. Schroeder, Ph.D. was in 1998 when I joined the faculty at the University of Kansas Medical School. Steve invited me to present at KU's Human Development and Family Life Professional Seminar. When I arrived for my talk, I scanned the audience and observed a Who's Who of pioneers in behavior analysis: Mont Wolf, Don Baer, Joe Spradlin, Steve Schroeder, to name a few. Half way through my talk, Steve asked a question about a potential negative side effect of the functional analysis procedures I employed in the experiment. Unfortunately, being that I was a tad "green", I provided a curt response to prevent the talk from going in a direction that I had not prepared for. As soon as I finished my retort and observed the response from the audience, I quickly realized that I had just offended someone (probably several folks) that I had a lot to learn from. I assumed that I was "done" with Steve after that mistake. I was wrong again. Steve proceeded to spend the next 15 years mentoring me in the art and science of conducting research that moves beyond the confines of the pages of our scientific journals. The capstone to our time together was one of the most meaningful experiences of my professional career – our work together at the Centro Ann Sullivan del Peru on risk markers for emerging self-injurious behavior during early childhood years. The easiest way for me to conclude and summarize Steve's career is that he always gave more than he took. Rest in peace, my friend.

### **Dr. Jennifer Zarcone**

I was very fortunate to have Steve Schroeder as a mentor in my life right at the time that I could truly benefit from his wit and wisdom. I was early in my career as an assistant professor at the University of Kansas and Steve had hired me work on his "chronic aberrant behavior" or "CAB" NIH Program Project. Not only did Steve give me guidance and support as I wrote my first *funded* grant (a supplement to the Program Project), but he also gave me guidance in how to identify my strengths and weaknesses to direct my career. We used to meet 2 or 3 times a year at Rosedale Barbeque in Kansas City, Kansas for a plate of burnt ends (which is actually better than it sounds) and iced tea. Steve referred to these meetings as our "karma" meetings. He would ask me how things are going not just with my job but more broadly with my career; what were my successes and failures and what were the next steps to which I aspired. At the end of our lunch, we would create a list of "next steps" for both of us. That was one of the wonderful things about Steve, he would use his networks and contacts to help make positive partnerships for myself and my colleagues. Many mentors might just give advice, but Steve actually helped to make things happen for me. So now I hold my own "karma" meetings with the students and staff that I work with and help them think through and prioritize where they want to go professionally. I hope that one day I will be the kind of mentor for them that Steve was for me.

### **Professor Johannes Rojahn**

In September 1976, just after having earned my Dr. Phil. in clinical psychology at the University of Vienna (Austria), I applied and was awarded a Fulbright-Hays post-doctoral Research Fellowship. My mind was set on the University of North Carolina at Chapel Hill. The person who gracefully accepted my application (with some apprehension as I was later told) was Steve's wife, Carolyn Schroeder, pediatric psychologist, Assistant Professor, and psychology post doc supervisor at the DDL (Division of Disorders of Development and Learning). Soon it became apparent, however, that I lacked the requisite clinical experience for her post-doc program, so Carolyn introduced me to Steve, who kindly took me under his wings. At the time, he was winding down a State demonstration project at Murdoch Developmental Center in Butner, NC developing service models for the treatment of chronic and intransigent SIB. Carolyn and Steve turned into good friends and they became godparents of our daughter. We kept in close contact even while my family and I had to return to Europe (Germany) for five years for visa reasons. He was instrumental in my return to the US (Western Psychiatric Institute & Clinic, University of Pittsburgh), and three years later, as the director of the Nisonger Center at the Ohio State University he hired me again. We collaborated continuously over the years and coauthored a number of papers, chapters, and a book. In short, Steve Schroeder was an influential presence throughout my entire career, and I will never be able to pay him back. He was a kind and wise supervisor, a great boss, and a wonderful and generous friend. I will always miss him.

### **Dr Travis Thompson**

Steven Schroeder is remembered as a modest man, noble of spirit. His early studies were models of translational operant research, people were assembling snap leads, reinforced under simple reinforcement schedules. The simple elegance of those studies was matched by the complex perspicuity of later biobehavioral research on self-injurious behavior. He urged others to join him in advocating for research funding at NIH. His advocacy was, in the final analysis, always for those who suffered most, those with severe developmental disabilities facing excruciating challenges. He was a generous teacher and leader of others. Above all, he will be remembered for the common decency with which he brought the tools of science to bear on improving the lives of people with autism and other developmental disabilities. He will be missed dearly.

### **Dr Andrea Courtemanche**

There are few times in my life when I distinctly remember being in the right place at the right time. One of those times is when I met Steve Schroeder. I don't remember why I was at that meeting or what was discussed, but I met Steve, he gave me his most recent book on self-injurious behavior, and we were off. For the next six years, we had a standing meeting on Fridays. During those meetings, we mostly talked about research, aberrant behavior, and psychotropic medications and we got excited over re-reading old books and seminal articles. We also talked about other things like Steve's travels around the world, his pioneering work in Saudi Arabia and Peru, hunting and fishing trips, and KU basketball. One of the things that strikes me most whenever I talk of Steve with other colleagues is that we all share a similar story where Steve had gone out his way to do something incredibly wonderful and selfless for each of us. Although his loss creates a void, Steve has left a legacy of dedicated, well-trained students to follow in his footsteps. I'll never be able to thank Steve enough for his mentorship and influence in my life and for his immense contributions to the field of intellectual disabilities. I think it's safe to say that many people's lives are better because of Steve.