

Face to Face

Prosopagnosia Research & Community



Welcome to the second edition of *Face to Face* and the first of 2011 – Happy New Year! We have many exciting research projects developing this year, and we are delighted to bring you great articles from both researchers and individuals with prosopagnosia in this newsletter.

We hope to hear any feedback you may have!

-Prosopagnosia Research Center (faceblind@faceblind.org)

CHILDREN AND PROSOPAGNOSIA

Research on face blindness (prosopagnosia) has flourished in recent years. Although traditionally studied in adults with brain damage (acquired prosopagnosia), it is now well established that face blindness often occurs from an early age, without any known brain injury (developmental prosopagnosia). Surprisingly, little research has investigated children with prosopagnosia; it is therefore important that we learn more about prosopagnosia in children to better understand the unique challenges they face, to identify ways to help them, and to better understand how prosopagnosia develops. In particular, an inability to recognize faces results in difficulties at school – the child may not recognize his or her teachers and he or she may struggle to make friends because of an inability to identify peers from one day to the next. Also of concern is that these children could be at a greater risk of “stranger danger” – they may not distinguish strangers from friends or family and so may put themselves at risk.

Brad Duchaine’s Social Perception Laboratory at Dartmouth College and Al Yonas’ Visual Perception Laboratory at the University of Minnesota are among the first to study large groups of children with prosopagnosia. Among the top priorities for these labs is the development of sensitive tests of face recognition for children. These tests will be designed to assess the ability to recognize facial identity, facial expression, gender, and non-face

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A CONVERSATION WITH DR. OLIVER SACKS

Oliver Sacks is a behavioral neurologist, best-selling author, and professor of neurology and psychiatry at Columbia University. Dr. Sacks also happens to have developmental prosopagnosia, and has chosen to write a chapter of his new book - *The Mind's Eye* - about his personal experience with the disorder. Before publication he sent the chapter to Ken Nakayama for review, and for obvious reasons, it piqued our interest. On October 29, 2010, the day of the book's release, we sat down with Dr. Sacks and his long-time assistant, editor, and friend Kate Edgar, to chat...

When and how did you come to realize you had prosopagnosia?

Dr. Oliver Sacks: I always knew I was rather bad at recognizing people, though I didn't recognize it as a physiological condition (although it caused me a lot of embarrassment.) People who knew me would say in advance, "Don't be offended if he doesn't recognize you."

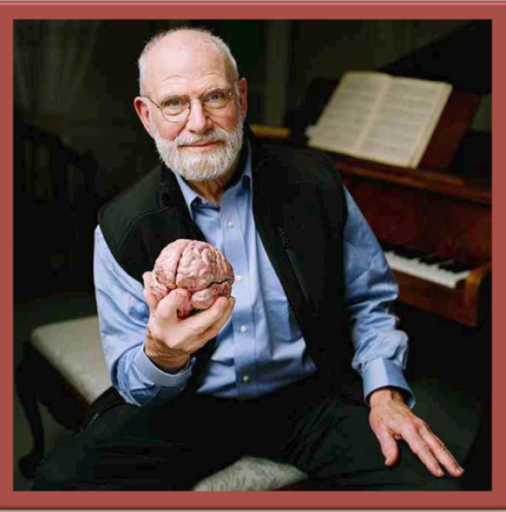
Only when I met my brother [after many years apart] did it gel for me that we both had something that the rest of the family didn't have.

Kate Edgar: We used to put it down to "absent mindedness."

OS : At the book signing the other day someone who I had been in high school and college with more than 60 years ago came up to me and said that although we often met, I'd never recognized him.

(continued on Pg. 2)

Oliver Sacks, continued from pg 1.



Many people are familiar with your writings on visual agnosia in "The Man Who Mistook His Wife for a Hat," published in 1985. What made you wait 25 years to write about your personal experience of prosopagnosia?

OS: I'm not sure of the answer. It's something which was very much in my mind - I wrote about it but didn't put in *The Man Who Mistook His Wife for a Hat*. There was a book in 1993 or so - *Mental Lives* - that contained a fairly detailed study of a prosopagnosic woman - a psychiatrist, "Dr. S" - and in my review I said that Dr. S could be myself. I was surprised, at the time, when the author said that this was the first ever richly documented study of congenital prosopagnosia, because by that time I had already received dozens of letters [from congenital prosopagnosics]. About a year ago I had

written this piece [The Mind's Eye], and in January I gave it to my editor and they said it needed to be longer and could I write about anything else, and Kate and I looked at each other and said, "Faces!"

Ken Nakayama: Yes, that was around the time I wrote to you - I met a reporter in Boston who had been at a party with you and who told me you were prosopagnosic and I said, really? She said yes - he didn't seem to know who anyone was!

OS: In 1987 I was doing a radio program and a man called in and said he couldn't recognize himself or his wife and I said, "Why don't I meet you outside in two hours."

You vividly describe in the same book, in the chapter entitled "The Possessed," the different emotions on the face of a patient with Tourette's syndrome. How does your experience of noticing emotion in face differ from your experience of determining someone's identity?

OS: While I am poor at recognizing individual faces, I easily recognize defining characteristics of emotional expression—like raised eyebrows for surprise, smiles, frowns, expressions of disgust or disapproval etc – characteristics one can represent in an icon or cartoon (I recognize cartoons more easily than photographs). These are general expressions, present across all cultures, and to some extent in other primate species. My problem is with specifics – the thousands of individual faces one encounters in a lifetime, faces often only subtly different from one another, in contrast to the dozen or two strongly marked expressions which define our emotional repertoire.

Though it is clear that there are salient social consequences to having prosopagnosia, do you think your experiences with prosopagnosia have helped you to become the accomplished author, neurologist, and observer of human behavior that you are today?

OS: My immediate impulse would be to say no, but I will have to think on this and get back to you.

How do you cope with your face recognition difficulties?

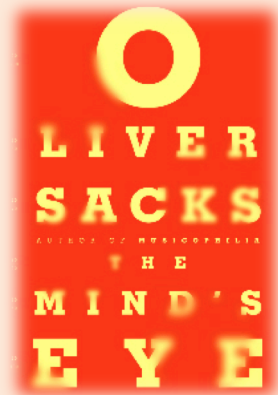
OS: Partly by conscious attention to postures, mannerisms, behaviors – along with dress, voice and context; partly by having someone with me who can serve as a recognizer; and partly by reclusiveness and withdrawal.

Oliver Sacks, continued from pg. 2

Do you have a favorite - perhaps funny - anecdote regarding an experience with failing to recognize someone?

OS: The most bizarre – and sometimes comic – instances have been failures to recognize myself in a mirror, or to mistake someone else for me, as described in *The Mind's Eye* on page 85:

My problem with recognizing faces extends not only to my nearest and dearest, but also to myself. Thus on several occasions I have apologized for almost bumping into a large bearded man, only to realize that the large bearded man was myself in a mirror. The opposite situation once occurred at a restaurant with tables outside. Sitting at one of these sidewalk tables, I turned to the restaurant window and began grooming my beard, as I often do. I then realized that what I had taken to be my reflection was not grooming himself but looking at me oddly. There was in fact a gray-bearded man on the other side of the window, who must have been wondering why I was preening myself in front of him. ▽



Children, continued from pg. 1

objects. Critical to investigations involving children, these tests will use images of children's faces rather than adults, have age appropriate difficulty, and will be adjusted to be more engaging for children. One of the primary goals of this work is to determine what underlies disordered face processing and what types of face processing difficulties exist.

Another goal for this research is to design and implement interventions to help rehabilitate children with face processing difficulties. The preliminary testing described above will provide information about the nature of the face processing deficits to help with the design of interventions and with the identification of candidates who will benefit most from these programs. Improved understanding of face blindness itself may allow for the design of rehabilitation strategies that are tailored to each individual's needs. Ultimately, the hope is that development of effective rehabilitation strategies for young children will help to lessen the impact of face blindness at all ages.

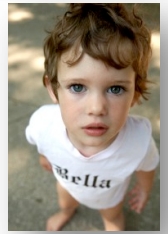
A parent recently shared with us her experiences with her prosopagnosic child. Please keep in mind that this parent's experiences and coping strategies may not be applicable to every parent and child.

Facing Prosopagnosia (all names have been altered for privacy purposes)

My son Ben was always a nervous baby, but it wasn't until he was about 2 years old that his difficulties really became apparent to me. He developed a very severe sickness, lasting weeks. When it had passed, he had gone from a rather highly-strung toddler, to one who was anxious, volatile, and socially odd for his age. It was on an internet support group that someone mentioned Face Blindness – and it was a Eureka moment for me. Of course! It made sense of so many of my experiences with Ben!

I have had some positive experiences with doctors, dietitians and pediatricians. I have also had some bad ones. The positive experiences were with health care professionals who listened carefully to what I had to say, asked intelligent questions, and then admitted frankly that they didn't have a clue. They admitted they did not have anything to offer, except referral to a consultant, who was also unlikely to have much experience with this particular condition. The bad experiences were with people who seemed to form an opinion very quickly - they did not listen, and did not take our situation seriously. They were on occasion

rude, dismissive, or patronizing. I have found being extremely well informed helps to get the most out of meetings with health professionals. Also having specific experiences to bring to the meetings helps. I found keeping a diary of the day's events and Ben's behavior very helpful. Face-blindness is such a weird thing to get your head around. If a health care professional has not come across face-blindness before, they need pretty good 'evidence' to take you seriously, rather than see you as an over-anxious mother with too much time on the wacky sites on the internet.



My best information has come mostly from other parents of kids/adults with prosopagnosia on support groups on the internet. I recommend joining Yahoo Groups, and then seeking out prosopagnosia/face-blindness support groups. Just looking through the archives and listening in on debates going on can be so revealing. My big breakthroughs about my son, came through someone 'just mentioning' face-blindness in the group - and I went 'Ah-haaaa'. Also by listening to others talking about their experiences I was able to see that some things I had taken to be 'just him' were in fact a symptoms. That is so easy when you have known them since they were born, especially if it is your first child.

I learned over the years to stop looking for someone in medicine or education who understands this to tell me what I was dealing with and how to help my son. I have instead turned to the internet where experienced families in the same position, generously share their knowledge and experiences to help those on the same path. God bless them – without them, I hate to think where we would be. ▽

In our first newsletter from Summer 2010, you may have seen a piece by Jo Livingston from England who is a great advocate for prosopagnosia research and the community, and is committed to raising public awareness. We encourage advocacy, awareness, and any actions like these around the world, and are very happy to provide support and information. If you might have the time and the commitment to take a leadership role in advocacy for prosopagnosia, could play a part in maybe creating a foundation in the US, and would like to discuss your ideas for such a role with us, write to us at sarahc@wjh.harvard.edu detailing what excites you about such a role and telling us about yourself.

Researcher Spotlight



Dr. Kirsten Dalrymple

Kirsten received a BSc from Queen's University (Canada) in 2004 before completing her MA and PhD at the University of British Columbia in 2006 and 2010. She recently started a Post-Doctoral Fellowship with Dr. Brad Duchaine in the Department of Psychological and Brain Sciences at Dartmouth College where she will study normal and abnormal face perception in children. Kirsten likes the outdoors, everything Canada, and globetrotting.

Dr. Albert Yonas

Albert Yonas earned his B.A. at the University of Michigan and his Ph.D. at Cornell University in 1968. Over the years he has carried out studies of perceptual development. Much of this work has described the development of space perception in infants. Recently he has worked with Ken Nakayama and Sherryse Corrow creating measures of recognition memory for faces in typical children. Al is expecting his first grandchild this January!



Sherryse Corrow

Sherryse received her B.A. from Minnesota State University Moorhead in 2008 and is currently working on her Ph.D. at the University of Minnesota at the Institute for Child Development. She has been working on investigating the development of face processing and developmental prosopagnosia in children with her adviser, Albert Yonas since 2008.

Sherryse enjoys spending her free time with her husband in their new house!