

A Tribute To Robert Perske

Circles Network

A UK wide advocacy organisation



29th October 2016

A Tribute to Bob

Circles Network is a UK wide voluntary organisation based in Warwickshire, renowned for building inclusive communities on the foundations of justice, advocacy, empowerment and friendships.

Working with people of any age who are isolated or at risk of isolation, Circles Network has ground breaking expertise in the development of Circles of Support, Independent and Collective Advocacy, Person Centred Planning and Inclusion into the mainstream of life. Working in highly creative, entrepreneurial styles, we are dynamic and ever more determined to dream, dare and do.

Circles Network's Advocacy services promote independent and collective advocacy within the communities we serve. This is underpinned by a strong, person-centred focus.

The discrimination and stigma people with disability challenges or health difficulties face in society can leave them disempowered, disadvantaged and vulnerable. They can be marginalised by society, often poorly informed as to their rights and excluded from key decisions that are made about their lives. The challenges they face are to have their voices heard, their views respected, their access enabled and their interests defended. Independent advocacy is an excellent way to ensure that an individual's rights are upheld and that they receive the care and treatment that they are entitled to. Circles Network's Advocates facilitate the process to safeguard people who may be vulnerable or discriminated against, or who services find difficult to support.

Circles Network has provided advocacy as a direct support for disabled people, people with mental ill health and people with cognitive impairment and long term health conditions for 22 years across the UK.

We have been fortunate during that organisational lifespan to have been inspired by the writing and teaching of several wonderful people, those who have often risked ridicule and criticism for 'going against the flow' - taking a stand to improve the conditions and life experiences of people at risk of marginalisation.



Robert Perske's work, so beautifully and poignantly illustrated by his wife, Martha, has provided a fundamental pillar of learning for literally hundreds of our staff members and volunteers over all of this time. Their books and articles and the accounts we have been privileged to listen to from our good friends George Ducharme and Pat Beeman, have encouraged and nourished us through so many journeys of justice and hope in the UK.

Having learned from this wealth of information, driven so clearly by an unshakable belief in the rights of all human beings, I often wondered just what kind of couple Bob and Martha were and how they kept up that relentless drive to foster and focus on fairer treatment for all.

In April 2016 I finally got to meet Bob and Martha and their little dog Wolfie, at their charming home in Darien, Connecticut. It was a proud day for me and one that I will always remember. I got to personally thank this magnificent couple for their contribution to so many people's lives and to reflect back on how their work had influenced my own career. To be truthful, I couldn't actually hold back tears as I was given a guided tour of Robert's office by George Ducharme that afternoon. There, framed on the walls in chronological order were the references I'd so often used to illuminate a specific point, to inform a thesis or an article, to highlight the importance of human rights on a training session I was leading - or indeed, in the case of that most beautiful book entitled 'Circles of Friendship (1998)' - to show parents with disabled children just how important inclusion would be for their child's happiness. This man has made a massive contribution, often at risk to himself. He has spent a lifetime providing advocacy and truth seeking, being that voice for those without one, giving so generously and with such admirable intelligence, grace and humility. For me, he personified authenticity as he genuinely gave all that he had to give.



I am deeply honoured and altogether better for meeting both Martha and Robert and am thrilled to be attending his commemorative event on 29th October this year.

Mandy Neville
CEO
Circles Network

A sample of examples from across the pond

The following pages offer you snapshots of the power and strength that a good advocate brings to the lives of others.

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Stories Of Change

Story of Change - Mr Clarke

Mr Clarke, a long-term patient in Stratheden Hospital, Fife, Scotland, approached the advocacy service, to say he was really worried by other patients smoking inside the building; particularly at night in their bedrooms. He is a non-smoker and his room is situated upstairs in the ward. An Advocate spoke to the staff there and suggested that it might be a good idea to ask a fire-prevention officer to give a talk to the patients. The ward-staff agreed this may help with

the problem and the Fire-Prevention Officer brought along another fireman and with the whole ward present, gave a presentation including visuals, which showed the often fatal outcomes careless smoking can cause. This had a very positive outcome in the Ward. Mr Clarke is much happier now and thanked the advocate for making this happen. N.b smoking has now ceased throughout the hospital.

Story of Change - Mrs Smith

Mrs Smith had contacted the advocacy service stating concerns that she had with a forthcoming meeting involving her husband's discharge from hospital. Mrs Smith felt that pressure was being put on her by the medical profession to move her husband into a care home. The advocate met Mrs and Mr Smith before the meeting to discuss his views. Mrs Smith had acquired a flat so that she could look after her husband. However, there were some doubts from the Occupational Therapist and the Consultant about the suitability of the property and Mrs Smith's ability to cope with her husband's care at night. The Advocate asked if this was the least restrictive option and stressed nothing

else had been tried and if reasonable adjustments could be made along with a support package it would give Mrs Smith the opportunity to look after her husband at home. The ward staff then offered Mrs Smith the opportunity to stay overnight in hospital so that she could experience her husband's routine. The consultant and Mrs Smith felt this was a good way to acquire awareness of what would be required of her when her husband came home. Mrs Smith was very happy to be given this chance and said she would stay at the hospital straight away. Mrs Smith was very happy with this outcome. N.b Mr Smith still lives at home with his wife.

Story of Change - Elizabeth

The Circles Network's advocacy project was contacted by Elizabeth who wanted support to put in a housing application at an office that was further away from her than her local office. This seemed quite straightforward but when the advocate met with Elizabeth the issue was more to do with her confidence and mistrust. Two years previously, Elizabeth was going through chemotherapy treatment for cancer, she had been renting her present home privately with her partner but he had left her so the property was now unaffordable. Elizabeth had gone to her local housing office to hand in an application form she had been given and asked to fill in. She told the advocate that she had been treated very badly by two separate employees. They had both been very rude in their words and tone. Elizabeth at that time was still sick from her treatment and had lost her hair so she was at a very low point in her life. Elizabeth became tearful talking about what had happened. The advocate told

Elizabeth that she could see how painful this was for her. She asked if Elizabeth had thought at all about revisiting the local office as it was far more convenient for Elizabeth and may help her confidence. She said she had thought about trying that but was scared. The advocate assured her that they could go together and if Elizabeth felt unable to speak the advocate would state her points for her. She agreed and an appointment was made. The appointment with the Housing Officer went really well. The officer treated Elizabeth with respect. All the forms were completed and she was able to say what she wanted with help from the advocate. Elizabeth was very relieved to have gotten through the meeting with all the necessary forms completed and into the system. Elizabeth said, "I found advocacy extremely helpful. I felt supported in a situation I found distressing and difficult. Thanks".

Story of Change - Sarah

Sarah phoned the advocacy service as she had an upcoming health assessment regarding her benefits and wanted support with this. An advocate went out to see Sarah and talked about what she wanted us to support her with. Sarah said that she can get very anxious when in meetings and can forget things that she need to say as well as finding it hard to express everything properly. An advocate helped Sarah to write down everything that she wanted to bring up at the health assessment. Sarah said that she felt a bit better because she was worried that she would forget to say things on the day. An advocate met Sarah for her health assessment and she was told they were running at least 30 minutes behind but Sarah wanted to

stay and wait to get it over with. Sarah was very anxious and worried and asked the advocate to go through all of the points for the assessment. Sarah said she felt more at ease and prepared. After waiting for 50 minutes Sarah was taken and was able to answer some questions but became upset and distressed. The assessor said that she would end the assessment as it was too distressing for Sarah and said that she was going to recommend that Sarah was not fit for work yet. An advocate asked Sarah if she would like them to express her views and she said yes. An advocate expressed the points to the assessor. Sarah thanked the assessor for being understanding and thanked the advocate for their help.

Story of Change - David

David has had support from Circles Network's advocacy project since his transfer to Leverndale Hospital, Glasgow (a secure hospital), in 2014 at which point he was extremely agitated at times and found it very difficult to sit down and have a serious conversation with anyone. David was fairly limited in the things that he could participate in and would not consider joining in certain activities organised by occupational therapy or nursing staff.

When I started working with David, he had not long been transferred between wards. Since his transfer, there was a remarkable difference in David's ability to cope with situations and engage with staff. However, David would consistently express negative views towards being in hospital and a strong desire to have compulsory treatment measures removed. David used my visits to express his unhappiness and often became visibly upset during these conversations.

After some time, David and I agreed to have a discussion with his key worker, who talked us through all the progress that David had made since his transfer. She also discussed plans for the future. It became clear that David really enjoyed hearing about all the things that he had achieved. Although this was a very positive meeting, it did not affect David's views about being in hospital and on subsequent visits, he remained very frustrated and upset about having to stay in the ward rather than returning to live with family. I suggested to David that we contact his lawyer to discuss an appeal against his detention and he was very keen for this to

be arranged. This was not something that he had previously considered.

I met with David and his lawyer a couple of times and this helped him to feel that he had people who were listening to him. Another meeting was arranged a few months' ahead to discuss an appeal. When this meeting came around, David had made huge progress with his care plan and had been granted some time out of the hospital without staff present. This was a massive step for him. During the meeting with his lawyer he was focused on this achievement and asked us to write down for him all the things that he managed to do without the help of staff. I helped David to communicate all of this information to his lawyer who took notes for him.

At the end of the meeting, David was in great spirits and did not mention at all that he was unhappy in the hospital. He was delighted with being able to go out by himself and buy things that he needed from the shops. There was a dramatic change in his mood and he was focused on the positive things in his life, rather than the negative. David thanked me for helping him and we agreed that he would tell me all about his next outing. His lawyer noticed that David and I had an incredible rapport which meant that I could help him remember important information to discuss and better communicate aspects of his daily life. David will undoubtedly be in hospital for a long time but this marks a significant step in his progress towards moving back into the community.

Story of Change - Lorna

Lorna is a lady who has mental health issues and has a daughter with ADHD. When an advocate went out to see Lorna she told the advocate that she felt she wasn't being listened to by doctors and other medical professionals. Lorna explained that she wanted an advocate to attend an appointment with her for her daughter, to give moral support and to express views on her behalf. At the meeting, the advocate expressed the aforementioned points on behalf of Lorna who said that she felt listened to for a change. Lorna stated that it made her feel more confident to have an advocate there and said they were a great help.

Written by an Advocate...

Within previous reports I discussed a young person that Circles Network has supported throughout the self-directed support process to put into place suitable support. In the past this young man has been offered a support worker however, due to the individual's diagnosis of Autism he found working with another person extremely challenging. The only time that this young person feels comfortable and confident being around people is when he has his pet dog with him. His dog offered him a support that no other human being could do and had a very therapeutic way of working with him to allow him to express his views in very limited ways.

Unfortunately, as the dog was just a pet the individual would be unable to take him into shops, his doctors or college. A result of this was a sudden drop out of college, where he was succeeding, as he had to leave his dog at the entrance and manage the pressures of this social setting along. This individual who I will call Nigel for the purpose of this report requested a direct payment to purchase an Autism Service Dog which he has been unsuccessful in receiving. After working alongside him over a number of months to slowly put down on paper his thoughts towards this unsuccessful decision we lodged an appeal and this decision was changed in favour of Nigel.

In May 2015 Nigel and his mother travelled to Ireland to meet his Autism Service Dog, a golden retriever called Millie who Nigel trained with over 4 days before returning home. Nigel has since reapplied for college as he feels able to return with Millie's support and is pushing himself every day to enter social situations where he was previously unable to even consider.

This has been a huge success story for the Directions service and showed just some of the commitment that is invested into the individual's that we support. This also demonstrated that working at the individual's pace allows them to put their own views and opinions across which made all the difference.



Introducing Millie the golden retriever who is always at Nigel's side when he needs support.

Shared thanks are an added bonus.

good advocate



To Marita

I am happy to see you and glad to make you so proud

Helen.



DYING MAN GRANTED HIS FINAL WISH

By Susan Lochrie
slochrie@greenocktelegraph.co.uk

A MAN dying of cancer has been granted his final wish to move closer to his family — after a nine-month battle with housing bosses.

Allan McNeill and his wife Mary had been told by River Clyde Homes that he could not have a flat in Port Glasgow.

But the couple refused to give up, contacting First Minister Nicola Sturgeon as they continued to fight, and now their persistence has paid off.

Mary, 65, said: "We have been put through a terrible ordeal."

See Page 5



Victory Allan McNeill and wife Mary have won their fight with River Clyde Homes to move closer to family in Port Glasgow. Picture: George Munro

Dying granddad granted his final wish to move

By Susan Lochrie

slochie@greenocktelegraph.co.uk

A MAN dying from cancer has been granted his final wish to move closer to his family — after having to battle with housing bosses for nine months.

Desperate Allan McNeill and his wife feared it would be too late as they begged River Clyde Homes (RCH) to allow them a house in Port Glasgow.

Instead of getting help they found themselves dumped at the bottom of the housing list.

Then when they thought all hope was lost RCH did a u-turn and gave them the flat they longed for.

With First Minister Nicola Sturgeon set to take up their case and threats of a complaint to the public services watchdog the McNeills were given a house.

Now the couple, who are also still grieving for their son killed in a knife attack, today thanked the *Tele* and all those who have helped them.

Allan, 67, *inset*, who has now moved into his new flat Rowan Court, said: "I wanted this for Mary — I needed to know that she would be ok when I was gone."

"I wanted to know that my daughter was just up the road and Mary's sister is in the landing below."

"But it has been terrible what they have put us through."

Their torment began nearly a year ago when Allan, who suffered from heart and lung disease, was diagnosed with terminal cancer.

It came less than a year after their 29-year-old son was killed in an unprovoked knife attack in Glasgow.

The couple, who lived in Rankin Court, were desperate to move but River Clyde Homes refused.

Mary, 65, *pictured*, who suffers from agoraphobia, said: "I have had to fight and fight. We have been put through a terrible ordeal. It took nine months and finally they gave us the flat."

"It has just made such a huge difference to our quality of life. We are so contented now and we have a lovely view."

"I refused to give up. They thought that we would just go



Pictures:
George
Munro



away. I wrote to Nicola Sturgeon and her staff sent me a letter saying that they would take up my case. But in the end I didn't need her to."

"When I got the flat in Rowan Court I phoned her office to tell them it was ok, we had a house. They said if I need anything I just had to call."

Throughout their battle the couple were supported by the Inverclyde Advocacy project.

In recent months they were in the process of building a case to take to the public services ombudsman when River Clyde Homes invited them to a meeting to tell them there was a flat in Rowan Court.

Mary said: "I can't thank everyone who helped enough. The advocacy were amazing. We did finally get our move but we have been put through a terrible ordeal."

Advocacy advisor Amanda Corney said: "I am delighted for Mary and Allan. They have had a terrible time and deserved their move."

"We were glad to be with them every step of the way."

The couple say they are still highly critical of River Clyde Homes' handling of their case but praised one of the association's housing officers for his support since they were allocated the flat.

Julie Allison, tenancy services manager at River Clyde Homes, said: "Towards the end of 2015 we revised our exceptional need procedure and reviewed the family's case in light of that."

"We're pleased that under the new procedures they were eligible for a move to a home in Port Glasgow."

"Our lettings system is fair and equitable and one that is based on housing need."

"We're glad the family have settled into their new home and thank them for their kind comments about the help they received."

A variety of quotes from individuals who have requested the support from an advocate:

"Without circles advocacy I feel my case would have never been resolved or left unanswered. They helped support me". J.Cameron

"Having being an employer of PA's for a number of years I found myself in a position that I needed some help and I contacted Advocacy. This is when I met my advocate, who I found very approachable. My advocate helped me immensley and supported me to get the information I needed, I could not have done this without my advocate." M.Mcelveny

"I would like to thank my advocate for taking the time to come and visit me to discuss my matter and for taking the time to contact the departments I was having issues with, and for his phone calls and follow ups I felt I was in charge all the way." B.Mallon.

"I could not have gone to anywhere more helpful in Scotland."

"My advocate was calm, cheery, compassionate, knowledgable, articulate, determined to get the answers. My advocate succeeded where I failed to get the answers - the firm involved made a big mistake, (inspite of their award for excellence) they hadn't the decency to apologise! My advocate changed the outcome for me."

E.Heavenor

"I am not a very confident person, dealing with problems etc, so the service was invaluable to me and my wife, who always dealt with our personal stuff, but after a stroke she's not able to deal with them herself now. So I wish to thank my advocate and the service for sorting our problems."

Owen & Jackie

Poetry by Jessie

The team at Circles Network Advocacy in Fife are delighted and proud to have been given some poetry by Jessie. The team would love to share them with the readers of this report. Below are examples of her work.



Down The Asylum

Teabags hanging up to dry!
Fill my pipe and my papers too!
Smoke my fill and a cuppa to boot!
I am skint! This is my way!
Smoking teabags every day!
When my shrink asks me how I am?
I wonder what he will make of me.
"I smoke teabags! and Drink tea"
Sectioned or committed I visualise,
Tablets increased or maybe a jab!
Poverty and madness I symbolise!

Care In The Community

Desperate to talk! The Walls don't have ears!
Isolation regenerates her fears!
No credit on her mobile!
Yet, she dreams of texting the night away!
Nobody bothers anyway!
Her landline never rings!
Telephone, off the hook!
Care in the community has its downfalls!
Put out to pasture in her youth!
No job, no prospects that's the truth!
Mental illness took her life away!
Twitching and shaking, every day!
Side effects she has to endure!
Charity shops and being poor!



Flashbacks And Dreams

Bikini clad, on a foreign beach,
Flashback land, out of my reach!
Little black number, I had style,
On the dance floor for a while,

My self-esteem was so high,
Never a cloud in the sky,
Size ten, I was so proud,
Standing out from the crowd

Bi Polar struck one rainy day,
My sanity was taken away,
Chaos, disaster, mad as a hatter,
My life it was shattered.

Pop a pill, make you smile,
Don't weigh yourself for a while
Size twenty, you will soon be,
Ill-informed is the key,
Researchers take up my plea,
Insanity verses dignity,
Drugs with a low weight gain potential,
Is essential with your Credentials

Dreaming of a petite size ten,
Feeling good, now and again,
Important to me, to stay well!
Alas side effects can be hell.

From fellow advocates in the UK

Thank you Bob, the world is a better place for many because of your words and actions.

With the highest regard,

The team at

Circles Network

www.circlesnetwork.org.uk



BOB PERSKE'S LIFE CELEBRATION

Saturday, October 29, 2016
Darien Community Association



Welcome!!

*Thank you for coming today to celebrate the life of **Bob Perske** - a man whose impact and contributions to all of us with and without a disability were both humble and powerful.*

*His close friend, Bob Williams, wrote:
"In his work - spanning more than 6 decades as a chaplain at an institution, an ARC executive, a community living innovator, a writer and a fierce friend of those falsely accused and condemned - Bob Perske constantly beckoned us to seek and seize a newer world of hope, opportunity and justice."*



“

***Be Kind To Everyone
Don't Leave Anyone Behind
No One Likes To Be Left
Behind ... ”***

- Bob Perske





Earth, Teach Me ...



Earth, teach me quiet – as the grasses are still with new light.

Earth, teach me suffering – as old stones suffer with memory.

Earth, teach me humility – as blossoms are humble with beginning.

Earth, teach me caring – as mothers nurture their young.

Earth, teach me courage – as the tree that stands alone.

Earth, teach me limitation – as the ant that crawls on the ground.



Earth, teach me freedom – as the eagle that soars in the sky.

Earth, teach me acceptance – as the leaves that die each fall.


Earth, teach me renewal – as the seed that rises in the spring.

Earth, teach me to forget myself – as melted snow forgets its life.

Earth, teach me to remember kindness – as dry fields weep with rain.

- A Colorado Ute Prayer

Program Specifics ~

- 12:00-12:30 **Karl Williams**, a singer songwriter – inspired by Bob Perske to create songs of inclusion, will play as we gather and throughout the program ... 
- 12:30 **George Ducharme** – Call to gather everyone through native drumming and poem – Earth, Teach Me ...
- 12:30-2:00 **FORMAL CELEBRATION OF THE LIFE OF BOB PERSKE**

“ In 2011, Bob left us this note that read,
I just finished digging through some old photos and... do you know what? I think I have discovered the “bookends” to all my remembered efforts. They began in 1945 and they ended a few weeks ago when the Governor pardoned Joe Arridy. Actually, as I look at the situation, I would like to extend the last bookend so it encompasses and liberates our friend Richard!!”
(last bookend realized on April 10, 2015)


Stories

This time will be filled with the stories and memories of Bob’s “remembered efforts” as told by his family, friends and colleagues.

Memories

2:00-2:30 Open for folks to share stories/memories...

2:30-3:30 Continue to share food and fellowship
Refreshments compliment of

~~~~~  *Michael Joseph's*  
FINE FOODS



Special thanks to Karl Williams for sharing his gift of music with us today!!

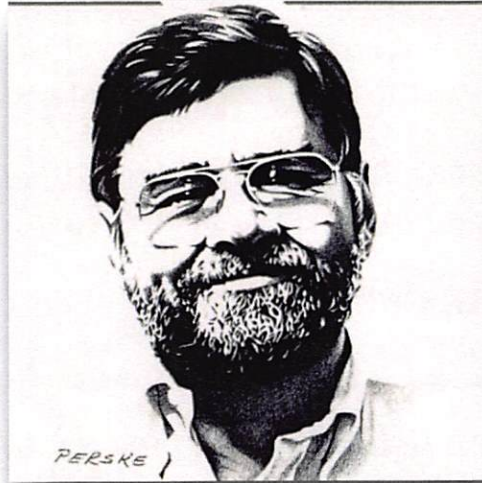


The Robert and Martha Perske Papers are part of the Special Collections and University Archives at UMass Amherst. A complete list of the collection can be accessed at:

<http://scua.library.umass.edu/ead/mums772>. Questions about the collection can be sent to [scua@library.umass.edu](mailto:scua@library.umass.edu)

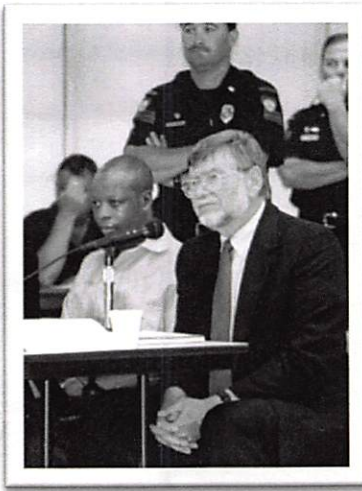


# ***“Thanks, Bob!!”***



***“A truly great man and advocate.”***

***“Your work help shape my thinking.”***



***“Bob you have created a movement that will live on, and the ripple effects are endless. We’ll keep the torch for justice lit brightly and keep passing it on!!”***

***“Thank you Bob for sending forward rays of hope to thousands of parents of children with disabilities.”***

***“Humble, generous and passionate spirit.”***

***“That man lived a wonderfully inspiring life.”***





*Achieve with us.®*



## Robert Perske Fund for Criminal Justice

**Robert Perske**, respected advocate and author, made his mark on this world in a way few others have. Bob was beloved in the disability community. His passion for making the world a better place for people with disabilities began when he read an article about a man in his community with intellectual disability on death row due to giving a false confession. He was hooked, and he never looked back.

Bob served as a chaplain at an institution for people with intellectual and developmental disabilities (I/DD), became an Executive Director for a chapter of The Arc, and authored ground-breaking books on creating circles of support for people with disabilities living in the community, and later in his life, books about people with I/DD coerced into giving false confessions and facing the death penalty.

Bob's deep compassion for and commitment to people with I/DD in the criminal justice system sent an undeniable message to society that every person's life counts. This unshakeable belief was contagious and sent ripple effects through both the disability community and the world of criminal justice and began a movement that culminated in The Arc opening the National Center on Criminal Justice and Disability®. Bob's fierce commitment to justice for people with disabilities will far outlive his brief time on earth, and his legacy will live on in the countless advocates who will carry on his work.

Martha Perske and her family are working with The Arc to continue to honor his legacy and keep his important work alive. Please consider providing a gift in his memory to the **Robert Perske Fund for Criminal Justice**. This will ensure Bob's passion for the rights of people with I/DD in connection with criminal justice will continue.

**To make a donation in Bob's memory please visit:**  
[thearc.org/perskefund](http://thearc.org/perskefund)



*For people with intellectual  
and developmental disabilities*



***Be kind  
to everyone***



***Don't  
leave  
anyone  
behind***



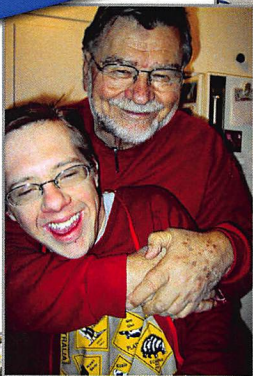
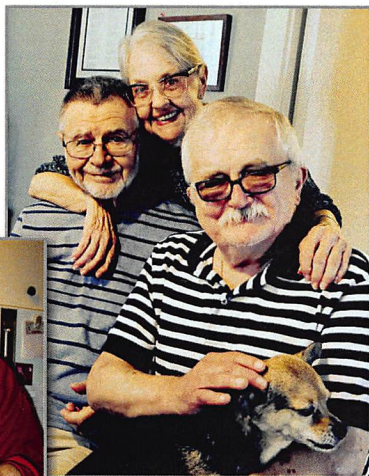
***No one  
likes to be  
left behind***



# Bob Perske Life Celebration

## October 29, 2016

be  
kind



be  
kind





**THE EXECUTION OF TRUTH**  
**The Criminal Justice Papers of Robert Perske**  
**Karin Melberg Schwier, Editor**

**SYNOPSIS**

As a result of what author and advocate Robert Perske saw as a catastrophic miscarriage of justice in 1980 in his quiet hometown of Darien, Connecticut, his writing took a significant turn in focus. For over two decades since, Perske has been driven to follow, work with and write about persons with intellectual disabilities who have encountered the criminal justice system in the United States. It has been an attempt, he says, to search for light in dark places. This book offers some fresh and current views on what happens today to people with disabilities who find themselves tangled with the legal and judicial systems, and it offers a collection of salient and thought-provoking papers that provide a wealth of experience, background and insight into this dangerous side of inclusive life in the community.

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## ABOUT THE AUTHOR

**Robert Perske** tracks, works with and writes about persons with intellectual disabilities who were coerced into confessing to murders they did not commit as well as those on death row. He has directly or indirectly followed over 100 of these cases.

Perske served with citizens and professionals who helped Missouri Governor Mel Carnahan pardon Johnny Lee Wilson. He founded The Friends of Richard Lapointe that was described in the 60 Minutes presentation, *Did He Do It?* (CBS/TV, 6-30-96) as well as in the Emmy-winning documentary, *A Passion for Justice* (PBS, WEDH Hartford, 11-29-94).

His earlier working career included:

- Amphibious Communications (WWII, Manila, U.S. Navy)
- Police Communications (Colorado State Patrol)
- Ministry (The United Methodist Church)
- Institutions (Kansas Neurological Institution and The Menninger Foundation)
- Community Services (The Arc of Omaha)
- Accreditation Surveys (Accreditation Council for Services for Persons with MR and DD)
- Writing Project Director (Random House, Inc.)

In 1968, Perske received the Rosemary F. Dybwad International Award for traveling and studying mental retardation programs in Sweden and Denmark. This early experience influenced many of the later directions in his life.

Robert and his illustrator wife, Martha, received The Healing Community Arts and Letters Award for their work in the developmental disability field, at the United Nations (May 19, 1987). In 1999, The National Historic Preservation Trust on Mental Retardation honored Robert and Martha as two of the 35 persons who made major contributions in the field of intellectual disability in the 20<sup>th</sup> Century. Perske was the first non-lawyer to receive the American Bar Association's Paul Herne Award, Washington, DC (August 12, 2002).

He currently serves as a visiting faculty member of the National Academy of Equal Justice, Temple University.

During the past 40 years, Perske has written 16 books and has been a constant writer of articles that focus on the critical human situations of persons with developmental disabilities.



## ABOUT THE EDITOR

**Karin Melberg Schwier** is an author and illustrator whose most noted works are about people with intellectual disabilities.

She has followed in the footsteps of narrative interviewers such as Studs Terkel and Robert Perske in the belief that stories told by people at the heart of issues are the tools by which to better appreciate, celebrate and understand the human condition.

Some of her publications include *Breaking Bread, Nourishing Connections: Mealtimes for People with and without Disabilities* (with Erin Schwier Stewart, Brookes Publishing, in press); *Sexuality: Your Sons and Daughters with Intellectual Disabilities* (with Dave Hingsburger, Brookes Publishing, 2000); *Idea Man* (Diverse City Press, 1997); *Couples with Intellectual Disabilities Talk About Living and Loving* (Woodbine House, 1994), winner of the CACL award in its first year of release and, in 1995, winner of the Joan Kershaw Publications Award from the Canadian Council for Exceptional Children.

In 2003, she received support from the Saskatchewan Arts Board to complete her novel featuring a young woman with an intellectual disability, her first major work of fiction.

Melberg Schwier has been the editor of a magazine published by the Saskatchewan Association for Community Living, an advocacy organization for people with intellectual disabilities and their families, since 1982.

She is the stepparent of Jim, 30, a young man with an intellectual disability, Erin, 27, and Benjamin, 23. She lives in Saskatoon, Saskatchewan, Canada, with Jim and her husband Richard, a professor of education.

[www.homepage.mac.com/karin.schwier/copestone.html](http://www.homepage.mac.com/karin.schwier/copestone.html).



# INTRODUCTION

## Why Bob Does What He Does

**By Karin Melberg Schwier**

My husband and I share a disturbing dream. It's the reoccurring sort where you startle yourself awake by a catch in your throat, a cold sweat and an urgent need to throw back the covers. Afterward, it's difficult to salvage any kind of healing sleep for the rest of the night.

At the dark center of this dream is our son Jim. A personable guy at 30 years old, he's a veteran volunteer at the YMCA. He's always willing to help around the house with chores and loves to pitch in for friends and neighbors who need lawns raked, snow shoveled, children read to, cars cleaned. In our dream—as it is in reality— Jim is most often smiling, wanting to help, offering assistance to anyone.

Here our dream takes an unsettling turn. We see Jim, uncomfortable now. Someone is there with him. Jim's smile a little stiff and uncertain, but still fixed in place. "I'm not sure what you want," he thinks, "but if I'm agreeable, I know you'll like me better. If I'm agreeable, I'll get it right. I've been taught to be polite and to use good manners." We watch him as he searches for clues about what to do next. He ties himself up in knots with a story that makes little sense, just hoping he'll hit on the right answer. Then his smile is gone and he's calling for us. For some reason, we can't help. We can't get to him. That's when we have to wrench ourselves out of this dream. We comfort each another that we have taught Jim well. His family has helped him become self-assured and confident. We try to create a life for him where there is manageable risk. We nurture a network of friends who care about what happens to him. We think he can't get into trouble.

But we are sobered by the thought there are families everywhere who once felt as we do. That their child would be safe and secure in a community that understands and accommodates. But then their world shifted on a point in time. Just a moment in a day when their son or daughter was in the wrong place at the wrong time. Maybe they witnessed a bad thing. Maybe they were lured into a situation where the consequences were too complicated—too horrible—to fully grasp. Someone accuses. A police officer asks for help. The world shifts when the child, always taught that the police will help, is too willing to be the helper.

For close to 40 years, Robert Perske's advocacy journalism has lovingly celebrated the value and worthwhile contribution of people with intellectual disabilities. His best-selling books have been the Bibles that have instilled a deep sense of equality and civil rights in families, friends and neighbors in ordinary neighborhoods. His words have guided the way they move forward with someone who has a disability. Bob's books have sold well over 250,000 copies around the



world and his poetic message has reached deep within us to strum chords of common humanity.

But in 1980, a catastrophic miscarriage of justice in his hometown of Darien, Connecticut took hold of Bob and wouldn't let him go. For over two decades since, Perske has been driven to follow, work with and write about persons with intellectual disabilities who have encountered the criminal justice system in the United States. It has been an attempt, he says, to search for light in dark places. He has turned to face the darker side of community inclusion certainly not because it is easy, but because few dare to look there. He has pulled back a shroud to allow us to see, understand and remember what can happen to vulnerable people who become targets for manipulation and abuse. He shows us what happens to people who become tangled up in the criminal justice system. He shows us that the very skills we teach people to live good lives in the community are the ones sometimes used to segregate them, abandon them, imprison them, and even put them to death. It is a disturbing, intimidating side of community inclusion that few of us want to think about but, as Bob says, "we've got to go in there. We've got to."

*"Not so very long ago, I left a courtroom trial in a far west state. I noticed that all the seats behind the defendant with retardation and his lawyer were vacant. The seats behind the prosecutor were packed. Having witnessed this phenomenon before, I visited the executive director of an agency who at one time served and supported the defendant. When the exec was told about that day in court, he suddenly responded like a cow watching a passing train. Then after a long silence, he said, "John isn't in our population anymore. He belongs to the police now." That response is understandable. Most people in the field of mental retardation feel that way. I felt that way once—until a painful arrest and conviction of a person with a mental disability in my own neighborhood grabbed me and refused to let me go. So it goes.*

*I follow and write about persons with intellectual disabilities who are suddenly caught up in America's criminal justice system.*

*I follow them on the street.*

*I sit behind them in courts.*

*I visit them in prisons.*

*I have followed some to the death chamber.*

*Society tends to type and classify them according to clinical labels—mentally retarded, learning disabled, developmentally disabled, brain damaged, autistic, or a whole slew of syndromes named after long-dead doctors.*

*I get attached to a person in trouble. Using my own skills and energy, I try to give what amounts to a cool cup of water to a person thirsting for some form of justice*



*he or she doesn't have. Others must try to deliver what amounts to cool, healing and sustaining cups to everyone in a neighborhood who thirsts in the same way."*

Every weekend—every weekend—Bob kisses Martha goodbye and pats former-street mongrel Wolfie on the head. Usually, he tosses his bag into the back seat of the Perskes' dilapidated Honda and sets out for the two-hour up, two-hour back drive to the north of Hartford. Prison rounds. The old '89 Honda replaced the smashed up, hung-together-with-baler-wire Mazda that finally gave up the ghost. If Martha needs the car, Bob crosses the street and stands on the Noroton Heights train platform with his beat-up briefcase. Off to the prisons, the sounds of keys clanking, barred gates clanging shut, searches by guards who now recognize his as a friendly face, the smiles that appear on the faces of those who call death row their home—all familiar territory now.

*When I go, I do everything possible to empty out my head and be ready to listen to the thin, almost inaudible screams for respect and understanding from the prisoners I visit. These are communications that most folks in the free world never hear or care to hear.*

Recently, one of Bob's former editors at Abingdon took him for lunch. The publishers of his best-selling and inspiring *Hope for the Families*, *New Life in the Neighborhood*, *Circles of Friends* and others, lamented the fact that Bob had neglected his more upbeat writing to focus on people in trouble with the criminal justice system. "Bob," the editor worried, "when are you going to write happy books again?"

Bob just smiled. Closing in on 80, he has decided with a calm resolve that he must craft the words to have a new impact, perhaps his most powerful legacy. What he wants to leave behind now is a new perspective on the neighborhood and a glimpse of what may be lurking there if we don't do something about it.

*"I gotta do this with whatever time this old geezer has left,"* he told me in my living room earlier this year. So intent is he on grabbing the public around the throat to make us see what happens to vulnerable people that he flew to my home in Canada with a over 70 pounds of files in tow. He came a request that I edit this collection of his papers, a compilation that it will reach people who need to understand this issue. Bob is a sweet bear of a man; he is also a force of nature. It was an offer I couldn't refuse.

The urgency of his request was evident as we poured over his boxes of papers, books, articles and clippings, and videotapes. It was hard to explain to that editor, he said, that he can't let this go, not as long as there are Richard Lapointes who wait for his weekend visits, who wait for Bob and a handful of others to sit with them in their prison cells and behind them—on their side—in the courtrooms of the country, and who sometimes watch them die.



These are not happy, optimistic Perske stories about how people with intellectual disabilities add to the rich and vibrant life of our communities. They are frightening stories of manipulation, coercion, violence and inhumanity. Yet running through it all is a comfort to those so inspired by Bob's writing over the years. The answer to protecting people with disabilities from the travesties and risks inherent in the dark side of inclusion is not to return to the grim days of segregation. Though people with disabilities can be "shockingly defenseless," whether they are guilty or innocent of the crimes they are accused of committing, the community is still the place where a vibrant and enriching life is found. What we work towards is a free and secure society with a fair and transparent justice system.

The answer lies in the inspiration born of Bob's earlier books, the "happy" ones longingly recalled by his old editor. We must provide support and the creative solutions to meet the individual needs of people with disabilities. We must educate the public so they can appreciate the real contribution people with disabilities can make, how much their diversity adds to the life of communities and yet understand how vulnerable they can be to manipulation and exploitation. We must understand and interrupt violence in our communities so that we may all lead peaceful lives. We must circle people who have disabilities with friends so that justice can and will be done while a good life is lived.

*I feel you should get so close to some of the people you serve and care about that you will lose sleep, that thinking about them will keep you awake at night every now and then...I guess that's why I still latch on to individuals today. I will do it as long as I live. I want to be completely used up at the end of my career, used up from doing individual pursuits. I think if I croaked in an airport departure lounge, waiting for a plane to take me to visit my next prisoner, I would feel worthwhile.*

This book offers some fresh and current views on what happens today to people with disabilities who encounter the legal and judicial systems. It also offers a collection of salient and thought-provoking papers that provide a wealth of experience, background and insight into this dangerous side of inclusive life in the community. You will find that his first paper, *A View from the Street: An Attempt to Discern Areas of Movement Regarding People with Intellectual Disabilities in the Criminal Justice System*, to be an excellent overview of the issues to be discussed in later chapters. Throughout this staccato collection of articles, papers, testimonies and teaching materials, you will also find thought-provoking quotes and compelling sidebar stories from people who have worked in the courts, in prisons, in police departments, and as advocates and civil rights activists for people with intellectual disabilities. You will read the words of people with disabilities and their families whose lives became nightmares.

And so we present the criminal justice papers of Robert Perske. You may be compelled, as Bob is, to do something. Even as this introduction is written, a life

dangles from the IQ noose. Despite a 2002 U.S. Supreme Court ruling that the execution of people with intellectual disabilities (mental retardation) is unconstitutional, they left the definition up to the states. So arguments rage in a Texas courtroom over a couple of points greater than or less than the magic 70. This may determine whether James Clark is executed or is allowed to live.

One of the most important things you can do as you grapple with the words of Robert Perske in *Execution of Truth* is to think about people like James Clark, Johnny Lee Wilson, Earl Washington and Richard Lapointe. Think of people you may know who face daily struggles in a world where things are always a little difficult to manage. Think of people you know who are willing to give others what they want in a hopeful quest for friendship and acceptance. Take advantage of the light Robert Perske is casting over intimidating ground. Feel the intensity of purpose that is this man and you will never think about vulnerable people the same way again. Lose a little sleep. We guarantee what you are about to read will wake you up.

– Karin Melberg Schwier, Saskatoon,  
2004

Editor's note: In many instances throughout this collection, the term "mental retardation" is used with respect to people with intellectual disabilities. People we know have said loudly and clearly that being called "mentally retarded" is hurtful and dehumanizing. We respect this. In fact, Bob reminds police officers in the training academy that people with intellectual disabilities will often deny they are "mentally retarded" because of the stigma attached. It is an irony of community inclusion that as we support people to be proud and confident, we strip away a disparaging label that might be a protection under the law. While the label still exists in legal and medical circles, we include it here. We hope, however, that the voices of people with intellectual disabilities remind us that words—laden with stigma and misconception—can hurt. **People with intellectual disabilities are not naïve enough to deny they have a disability. Many people embrace it as a significant part of who they are. But they ask us to see them as a unique individual**