

## **Yom Kippur Morning 5770**

I love the haftarah reading for Yom Kippur morning. It is the essence of chutzpah, both in its content and its placement in the service. It portrays the prophet Isaiah as a classic rabble rouser, challenging the wealthiest and most comfortable of Israel's citizens on a day they appear to be feeling particularly smug. It is easy to imagine the outrage experienced by those who hear Isaiah reporting that God actually has no interest in how hungry the fasting worshippers might be. Some here might feel equally angry: at this time of day, when the hunger starts to bite, we'd really like to feel that it is important to God that we have undertaken this commitment. Instead, Isaiah states unequivocally that what God is really looking for is righteous action, not gestures. Our hunger on this day adds nothing to the overall improvement of the world if it does not compel us to work for justice when this day is over.

For seven years, I lived in the working-class town in western Pennsylvania where my little synagogue was located. Our town of 8000 housed a food cupboard that distributed emergency food supplies to an average of 100 households each month. There were lots of people without jobs and with little access to retraining. Because of the draconian American healthcare system, many people in the town were without any health insurance and suffered with untreated chronic conditions. Notices were posted regularly advertising spaghetti dinners to raise money for families whose finances had been devastated by serious illness. There were several antiquated playgrounds in poor repair and very few other places available for children to play. The community needs were very obvious and very overwhelming.

Three years ago, we migrated to Australia. When I first came here, the contrast with the United States was startling. There were so few obvious signs of poverty, of need. By contrast, indications of prosperity were everywhere. It was dazzling.

What I've gradually learned over the time that I've lived here is that there are serious unmet needs in Australia too, but they are usually hidden out of sight or far away from large urban centres. There is much misery out there, but we have to look for it. And there are few easy solutions to these intractable problems, and almost no

cheap ones.

I am betting many of you are very familiar with at least some of the many ways that Australia has failed its indigenous population. The more I learn, the more I am aware of how very complex this issue is. The challenges of closing the gap, not only in health, but also in education, income, and other measures of well-being, are extremely difficult enough to nut out. It's an indication of how multifaceted this issue is that we can readily find passionately committed activists who support the Northern Territory intervention and who oppose it, who support quarantining welfare payments and who oppose it. Recent stories in *The Australian* focus a spotlight on just how dysfunctional federal and particularly state governments can be when it comes to addressing desperate human needs. I do not claim to have the answers—not even one. I am pleased to see that so much attention is now being focused on this great social justice issue, and I hope that this continuing attention will eventually yield results.

But what I really want to speak about this morning are the thousands of people living in difficult circumstances right here in Adelaide. I speak of those who are caring for a severely disabled family member.

All of Australia was rocked several months ago by the news of a local mother who killed her severely-disabled 16-year-old son and then turned herself in to the police. I'm sure many of you are familiar with the story: her son had the mental capacity of a two-year-old and was prone to violent tantrums. As is typical in households where there is severely-disabled person, the responsibility for the young man's care had fallen almost entirely upon his family. After years of living with fear, anxiety, and unending exhaustion, the mother finally acted—in a way few of us could justify. An explosion of anguished letters to the editor of *The Adelaide Advertiser* followed, many from parents, siblings, and children who themselves had been pushed to the brink by the burden of caring for a profoundly disabled relative. Here is one of those letters: “The Eitzen family is by no means the only family where everything has had to be kept locked for years, where nothing is safe from destruction, where sleep is in shifts so that someone can constantly be on the alert. It is a seven-days-a-week, 24-hours-a-day reality for far too many people.

There are other families where there is no social life, where siblings cannot bring friends home or participate in outside activities, money is short and nobody has had a holiday in years, where the other children have to grow up rapidly and take responsibility for themselves far too soon.

This is the reality of living with a child who has severe behavioural and intellectual difficulties. This is what happens when governments take on a policy of “care in the community” and then use it as an excuse to do little—and often nothing at all.

The rest of us simply have no idea what it is like to love the child and hate the circumstances. Will this be a wake-up call for the Government and those who demand “care in the community” at whatever cost to others? I doubt it.

We also have to care for the family. It is something we spectacularly fail to do, too often with tragic consequences.”

I’ve become acquainted with an extraordinary woman in the Adelaide area. She takes her privacy very seriously, so I’m going to call her M. Having raised their own children, she and her husband have started over again. They now look after five young people with severe physical and mental disabilities. They’ve adopted several of the children, and the rest are in their care as foster children. M. recently shared with me some of her frustrations: she cares for a boy who is unable to move unaided. If left in one position for too long, he develops pressure sores, which are quite painful and very difficult to treat. His wheelchair doesn’t fit him properly, and so he can only sit in it for an hour before he needs to be taken out to avoid injury. She made a call early in the year to ask someone to come out and adjust the wheelchair so that it could accommodate this young man for more than an hour. Ten months later, she’s still waiting. She exclaimed, “The most severely disabled people always fall to the bottom of the list. I’m glad to hear that autism is now a recognised disease, and that treatment is available. But there are people out there with intense needs which simply aren’t being met.”

M’s foster and adopted children attend a special school for the disabled in the Adelaide area. She shared with me the reactions of parents to the story of the mother

who killed her son. A number of parents felt that they might end up in a similar situation. They understood the exhaustion and drain of years of caring for a disabled child, and worried that they too might be driven to the brink. Others thought they might be driven to this same drastic action for no other reason than they knew that their children would outlive them, and there would be no one to take over the care. M spoke of her adopted daughter, who is fifteen but has the mental awareness of a toddler. M's own daughter has agreed to take over this young woman's care when her mother dies, but there is no one to provide care should the daughter also die.

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Several times each week, I head over to the Unley Shopping Centre to do my shopping. Nearly always, someone is standing at the entrance holding a tin. I stroll down the entrance hall to Woolworths, and there's someone else in front of the shop with a tin from a different charity. Set up to one side is a table advertising still another charity. And I find myself thinking. Who decides which charities get a crack at shoppers? How much money is getting raised here? How much of a difference is it making? And who is being left out? Parents of severely disabled children, along with those caring for disabled adults and frail parents, don't stand at shopping centres raising money. They don't have time, and they certainly don't have the energy. Nor do they have time to write letters, to visit their members of parliament, to make a fuss. Mostly, they're just trying to make it through the day.

Many years ago, I was fortunate enough to enrol in a philosophy course taught by Laurence Thomas, a gifted teacher. In one lecture, he spoke about Dr. Martin Luther King, Jr., America's best-known civil-rights leader. Dr. King's greatness, said Professor Thomas, lay in how he understood the profound impact equality for African Americans would have on all Americans. He did not argue that America should grant equal rights to blacks because they deserved it. Instead, he fought on behalf of equality for African Americans because it would benefit all Americans. Elevating one group within our society makes a difference to all of us, even if our paths never cross.

As it currently stands, there will never be enough money in either the state or federal budget to meet all the needs. What happens instead is that one very worthy

cause is pitted against another. Like the competing charity tins in the shopping centre. I subscribe to an e-mail listserve that looks at issues specific to disabled children. A number of months back at budget time, the father of a child with Asperger's Syndrome posted a note calling on like-minded parents to storm Parliament House to advocate for appropriate funding for these needs: He wrote, "Let's go and get our money!" I was horrified at how crassly he'd worded his proposal, probably even with the understanding that money used to assist children with Asperger's Syndrome would not be available to others who might be equally or even more needy. Surely there must be a better way.

As it turns out, there is. The solution is to adopt a national disability insurance scheme, comparable to what exists already in the U.K. Sue Corrigan wrote persuasively about the British system in her extensive article which appeared in *The Australian* back in March. When her son was diagnosed with profound neurological challenges as a child, she and her husband decided to move to England so that he could have access to appropriate care. Here is what she wrote: "We decided to leave our jobs, families, friends and the house we'd built and move to England so Shane could attend a genuinely special school we'd heard about, with daily therapy and teaching programs tailored specifically to children with cerebral palsy. Although extremely hard in many ways, leaving was far easier than staying. It felt like we were being driven into exile from our own country, but it also felt like we'd escaped.

In England we discovered that a well planned and adequately resourced disability support system doesn't have to be a pipedream. There is no exhausting fight for vital equipment or services. If you're assessed as needing something, it is provided, usually immediately – unlike in Australia, where so often parents are told, yes, they may well need something urgently and, good news, they do indeed qualify to get it ... except sorry, there's no money to fund it. It's not perfect by any means, but the English system is so much better than Australia's essentially because four landmark acts of parliament give people with disabilities and their families the legal right to whatever they are assessed as needing. No such legal rights exist in Australia."

Bill Shorten, a Victorian MP and parliamentary secretary for disability services, is pressing for a similar insurance scheme here in Australia. This would mean an additional levy, which is going to be less-than-popular. But is there another option? The website promoting such a scheme notes that all Australians are at risk of seeing their lives forever altered by a disabling illness or accident. Life changes enough when one is dealing with a disability. Racing around trying to secure desperately-needed services shouldn't have to be part of the equation. England has found a solution which works. If Australia wants to support some of the most vulnerable of its people, it should do the same.

We are at the opposite end of the year from Pesach, but there is a line from the Haggadah that I think powerfully addresses the challenges facing our society. The Haggadah states, "This year we are still slaves. Next year may we be free." Are we really slaves? Obviously not. But the implication is that so long as anyone out there is not entirely free, all of us should regard ourselves as still enslaved. Hundreds of thousands of carers here in Australia are not free to live the lives they dream of for themselves. We should do what we can to assure that all Australians have access to what they need so that all can share in this nations bounties. I believe Isaiah would approve.