

Providing Holistic Healthcare for Adults with Intellectual Disability

Text and photos by Dr Chen Shiling

He's been very agitated and has been grabbing dad's arms very tightly the past few months... it's been getting worse and more frequent... we don't know what to do...

L's mother shared this with me tearfully as she sat in the consult room, together with L and his father. She gestured at her husband, and I saw scratch marks and bruises on both his forearms. L sat quietly in his chair, not looking at me, while his father stood beside him, looking tense and emotional. L is 31 years old and has autism with intellectual disability. He is mostly non-verbal, though he can say a few words and use simple signs and gestures to indicate his needs and wants. He attended a special school and, since he turned 18 years old, has been attending a day activity centre for adults with autism. The diagnosis of autism years ago had been heartbreaking, but after the initial period of grief and pain, his parents had dried their tears and were determined that come what may, they would do all that they could for their son. In the years that followed, they surmounted obstacle after obstacle, and celebrated when L eventually settled down happily in his day activity centre, until the recent months. They now faced a new challenge – one that was affecting L at home and the centre. They had tried all the strategies they knew but none had worked. They needed help.

IDHealth and what we do

Reading L's story, the immediate thoughts that come to one's mind are perhaps "behaviour problems" or "sensory problems", alongside notions of psychologists, behaviour therapy and support for L's family. Indeed, these are natural considerations, but as a doctor attending to adults with intellectual disability, the thought in my mind as I sat in that consult room was the simple question, "Why?". Why is L behaving in this manner? Why is he hurting his dad whom he loves dearly? Could a health problem be the cause of these behaviours?

This manner of thinking is natural for medical professionals. We have always been taught to question, to look beyond the superficial symptoms to determine the root causes, so we can prescribe the most appropriate treatment. Furthermore, many of us would remember how we, as medical students, were reminded repeatedly by our professors that history taking is the most important part of medical consultations. Not the physical examination nor the investigations,

but simple history taking. In essence, the communication between patient and doctor is what will help us clinch our diagnosis. But how do we do this with L? Or with the many individuals with intellectual disability, who may not have the ability to verbalise discomfort, or for whom the word "pain" may not hold the same meaning as for you and me?

This is where IDHealth strives to make a difference. Having volunteered with persons with intellectual disability (PWIDs) since my teenage years,^a I have had the opportunity to see the multiple challenges they face in accessing healthcare. Their lifelong cognitive and communicative limitations, their ageing caregivers and the lack of knowledge and expertise among healthcare professionals are some of the barriers PWIDs continually face. With these in mind, I envisioned a clinical service that would cater to their needs while addressing these barriers. After many years of advocacy and working closely with governmental and non-governmental agencies, IDHealth finally became reality in 2022.



Person-centred and family-centric approach

As an interdisciplinary team comprising doctors, nurses, medical social workers and allied health professionals based in the community, efforts are made continually to overcome barriers through making reasonable adjustments such as allowing more time for consultation and utilising visual supports. Being person-centred and family-centric in our approach, one unique aspect of our service model is that in addition to seeing the PWIDs, caregivers also get enrolled as our patients if they have complex health needs. A 35-year-old adult with intellectual disability and epilepsy, and his 70-year-old mother who has recurrent falls, would therefore both be our patients. In this way, we manage their health needs not just as individuals but also as a family unit. We also match their care recipient needs and caregiver abilities, so we can support them in achieving their goals as a family.

In the situation of L, as none of his family members have complex health needs requiring our interventions, we would not enrol them as our direct patients but would support them closely in their caregiving roles. IDHealth also right-sites our interventions. What does this mean? For example, if a PWID with diabetes works in a supermarket, our team will visit him/her at the workplace to teach him/her appropriate lunch choices. This is important as PWIDs are environment specific and may not be able to apply at their workplace what they have been taught in the clinic or home setting.

As a team, IDHealth's goal is to provide healthcare for PWIDs and their families in a holistic and accessible manner, to bring about positive health and well-being. To this end, we straddle the health and social gap, working closely with partners across both sectors, integrating services to deliver the care that is required for this often forgotten and vulnerable group.

Path to diagnosis

After listening to the recounting of L's behaviours, it struck me that his agitation predominantly occurred around meal and toileting times. Careful charting of his behaviour confirmed this, and we eventually concluded that L had symptoms of constipation and



irritable bowel syndrome. A picture was emerging. Unable to make sense of nor verbalise his pain, L naturally turned to the person he relied on most in his life, his father. Each time the pain intensified, he grabbed his father in distress. With this working hypothesis, we started treating his constipation, his gaseous distension and his pain. It took an intensive period of close monitoring and follow-ups, but as his agitation reduced and his grabbing behaviour diminished, it became clear that we were on the right track. Together with his family, we also taught L how to request for medications whenever he experienced pain and discomfort. This opened a window of communication for him, allowing him to share with his family and his healthcare team what he was experiencing and what he required from us. In addition to his physical symptoms, L also experienced anxiety, and this worsened his gastrointestinal symptoms. After optimising the treatment for his physical discomfort, we decided to start him on anxiolytics as well. Over a period of approximately six months, L's agitation and grabbing behaviours ceased, and he was participative at his day activity centre again. When L came for his reviews with his parents, gone was the tense atmosphere. As L smiled at me and gave me a thumbs up, his parents grew emotional and said to me, "We've gotten our son back, he is happy again. Thank you."

Conclusion

L is but one of the many patients we see at IDHealth. Each has a unique story filled with uncertainty, challenges and heartache, but also immense resilience and joy. We, as a healthcare team, do not presume to be able to solve all their problems, but we can do our best to address the health problems that affect and impact their lives negatively. We can do this with understanding, patience and respect. Health permeates all aspects of our lives, and it can be distressing when ill health strikes any of us. For PWIDs who have little avenue

or resources to speak for themselves or advocate for their pain and suffering, health challenges can have even more devastating consequences for them and their families.

Caring for PWIDs with their many complex needs may not be straightforward, but what does it really demand of us? Recently, I had the opportunity to ask a PWID what in his opinion makes a good doctor. He said, "Someone who listens to me." How simple and yet how profound. I have always maintained that PWIDs teach us what it means to be human. After the privilege of seeing them all these years, I would like to add that they continually teach me what it means to be a better doctor too. ♦

To learn more about IDHealth and its work, visit <https://happeehearts.com/>

Note

a. Read more about Dr Chen's experiences in her previous SMA News article here: <https://bit.ly/4806-FTH>.

Legend

1. Nurse Pei Ing and podiatrist Toto persuading Hock Chay, a patient with Down Syndrome, to agree to podiatry treatment. Hock Chay insisted that they had to listen to his heart first!
2. Dr Chen using visual supports during consultation to engage Janine, a lady with high support needs autism. It was fun for both of them!

Dr Chen is a physician with special interests in dementia and adults with intellectual disability. She is the founder and executive director of Happee Hearts Movement. She is also an appointed member of the Adult Protection Team, Ministry of Social and Family Development, and a member of the 4th Enabling Masterplan (EMP2030) Steering Committee.

