

Lieutenant Governor's Project to Help Children with Developmental Disorders

An update for staff and aides, advisory board, and interested readers.

As many of you know, one of His Honour's themes is Disorders of Childhood Development. We have spoken about this on a number of occasions now, as you have seen on the website, www.lg.gov.mb.ca. It is our wish a) to highlight the good work that is already being done in Manitoba, b) to further the understanding that the children and adults with these disorders, even if they look like everyone else, have real brain disorders that impact their functioning, c) to encourage further action in the provision of services and environments that are helpful, and finally d) to provide concrete help to schools as they plan quiet learning spaces suitably furnished and equipped for those who cannot always work in highly stimulating classroom or recess settings.

Last fall, 2004, we visited The Pas and spent a day listening to presentations from many different systems serving children and adults with Fetal Alcohol Spectrum Disorders (FASD). In the winter, 2005, we continued to connect both formally and informally with people serving children and adults with FASD and Autism Spectrum Disorder (ASD). We began to attend occasionally the monthly Telehealth Link of the Autism Society. This is a two hour satellite television broadcast to 17 Manitoba communities that brings them interactive presentations about parenting and schooling children with ASD. To help us plan and carry out our five year theme, we invited four people to meet us regularly to discuss our actions in this regard. They are Dr. Jane Bow, psychologist from Autism Outreach at the Health Sciences Centre, Deborah Kacki from Fetal Alcohol Interagency Network, Cathy Cormier from Child and Family Services who sees from her parent perspective, and Lesley Hughes who is widely known locally and nationally for her presentations on FASD. We call them our Advisory Board. Secretary to this board is Phyllis Fraser, Executive Assistant to His Honour.

October 6, 2005 we hosted seventy five school superintendents, cabinet ministers and deputy ministers, for a dinner at Government House. His Honour spoke about our wish to raise awareness and be helpful with children and youth who have disorders of development particularly ASD and FASD. Guest speaker Dr. Michael McIntyre, neuropsychologist, gave a well received presentation about the need for understanding and adaptation of environments for these children. In his own research with brain imaging, he can see clearly that the brains of people with FASD for example, are very different from the brains of most people. Parts are actually missing, and this accounts for their inabilities in learning skills that we all take for granted – like the skill of learning from consequences. Just as we would not blame a child for having a disorder of the pancreas (diabetes), we should not blame a child for having a brain disorder. It takes the efforts of many helpful adults, supervising and teaching every day, to help such a vulnerable child.

People who have developmental disorders usually have strengths as well as difficulties. Finding and nurturing the strengths is what all professionals would like to do. In order to find the strengths of ASD and FASD students in schools, it is often necessary to provide

them with learning environments that are low in stimulation: quiet, non cluttered, with soft lighting, materials and furniture, and staff trained in effective methods. Calming environments curtail over-reaction and enable people to listen, concentrate or think things through. The project of the Lieutenant Governor will focus on helping schools provide alternative environments for the use of all students who could learn better by spending some time in such a space. We want to acknowledge that most of us need sometimes to pull away from the intense stimulation of the busy large group! Alternative environments in schools would no doubt be used by many people over time. However, they are essential for people like ASD and FASD students who can act defensively and disruptively when over-stimulated or confused. Such students may behave inappropriately when this could have been prevented.

This was the realm of discussion by Dr. McIntyre at the October 6 dinner. The dinner gave us the opportunity to share our interest and willingness to work.

The Lieutenant Governor's project now has a number of facets listed below. We would like everyone who works with us to have some idea what they are and what will happen next. Her Honour would be happy to answer further questions from anyone who is interested. Any staff member or aide who would like to be involved is also welcome to talk to her about possibilities. Lenore can be reached most easily by e mail at lenoreberscheid@yahoo.ca, and you can leave messages for her at the office, 945-2753.

1. Communication and teaming with the Department of Education. We will listen and respond to the needs of 15 schools that are re-thinking their structures with community needs in mind. By September, 2006, these Community Schools will have plans to serve children, youth, and families in ways that may include quiet learning spaces such as we have described. Watch this space for a link to the Community Schools Project.
2. Telehealth presentation of Autism Society of Manitoba. In early 2006, Her Honour with Deborah Kacki and Cathy Cormier from the advisory board, will give a two hour interactive presentation to the 17 communities in Manitoba that receive the closed circuit satellite Telehealth broadcasts. The presentation will be about developing calming environments at home and in school. Participants will be welcomed to stay in touch with us. Their Honours hope to visit many of the schools that access this program, to celebrate what they are doing. This presentation will, if possible, be recorded or repeated for other audiences.
3. In January, 2005, we will start to develop a network through which we can obtain donated materials to help schools set up the special alternative environments we have spoken of. By using our visits to sites, our website, word of mouth, and advertising, we will ask for donations of the specific materials needed at a site. It is likely that most materials needed at a site can be donated and delivered within the town or neighbourhood. However, we must be prepared for times when the local community does not have what is needed at the school. Already, two well established women's groups in Manitoba have come forward after hearing Her Honour speak about this project. They will meet privately to discuss how they can help find resources.

To overcome barriers of distance between donated materials and schools that need them, we will be locating transportation sponsors: companies and organizations that transport goods regularly and occasionally have empty space. To overcome barriers of time, when a donation is available now but the school cannot have its room ready for some weeks, we will locate storage sponsors: schools, warehouses, other safe places. We will begin in January to meet with organizations and individuals that have connections and expertise to help us with this infrastructure. We hope to have this in place by August, 2005. Then we will systematically take requests from the 15 community schools and from schools in the Telehealth communities. Where it is possible and deemed helpful, we will visit a school on an occasion and talk about what is needed. Orderly screening of goods, receipt of goods, and setting up of the rooms will be arranged with the local school. Training of staff is the domain of the Department of Education, and Her Honour may participate with Department personnel.

Naturally, there are many schools that have alternative environments already in place. Many more will go ahead with this service as a matter of course following the legislation requiring inclusion of all children in school all day (Bill 13). The Department of Education has prepared materials to facilitate the planning for this, and there are special documents for ASD and FASD students. The intention of the Lieutenant Governor and his team is to be helpful as much as possible. We see ourselves as members of the wider team of Manitobans dedicated to the education and citizenship of our children especially the most vulnerable.

4. The Lieutenant Governor's website will continue to add pieces to its link on ASD and FASD. The people working closely with us will offer short practical articles based on their experience and academic study. Professor McIntyre will offer an article about his research, and a bibliography. We will update the site when we have progress to report. We will report when we are ready to take donations, and exactly what is being requested by specific schools. Thank you for taking time to read this: we hope to see you again!