

Lessons Learned from Supporting Individuals with ASD Having Complex Needs

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**Provides specialized
supports and services
for individuals with ASD
across all ages,
in Canada's largest province,
Ontario.**

KPAS SUPPORT CONTINUUM

(based on least to most intrusive)

*Prevention < Early intervention < Primary clinical and
community support (e.g. residential) < Secondary clinical and
community support (e.g. treatment environments in community)
< Tertiary clinical support/hospital admission*

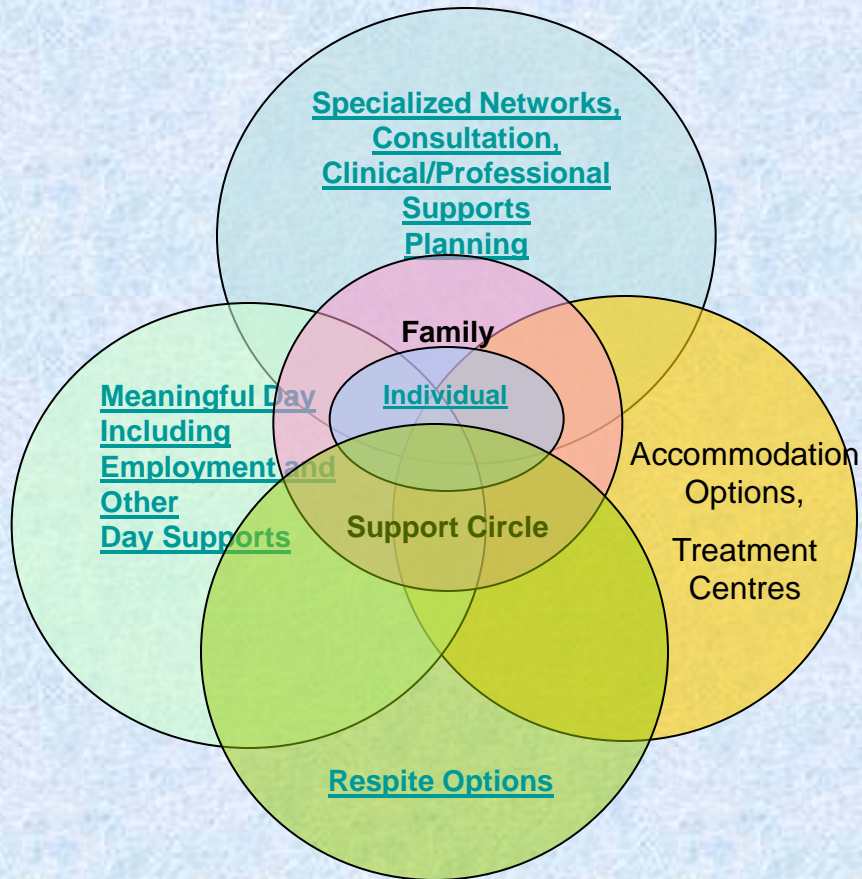
SUPPORT CONTINUUM

- **Need to deal with issues as early as possible on the continuum**
- **Prevention and early intervention too often don't happen in a timely fashion**
- **Lack of understanding of ASD often leads to the need for more intense support**
- **Important to continually endeavor to help each individual to move leftwards on the continuum, however slowly, one step at a time**

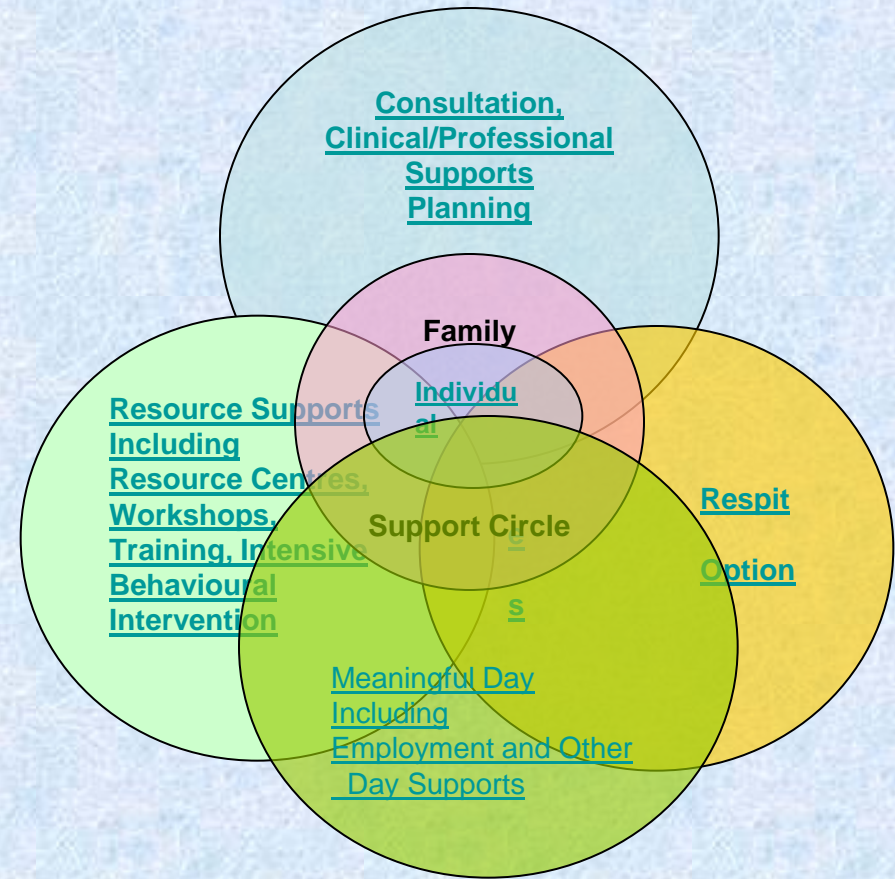
(see Howlin, 2002, for a brief review of intervention research)

Supports and Service Provided By Kerry's Place Autism Services

Residential Services



Community Services



NUMBERS SUPPORTED

- **Prevention and early intervention > 3,000 individuals**
- **Residential options > 150 individuals**
- **Treatment centres > 20 individuals**

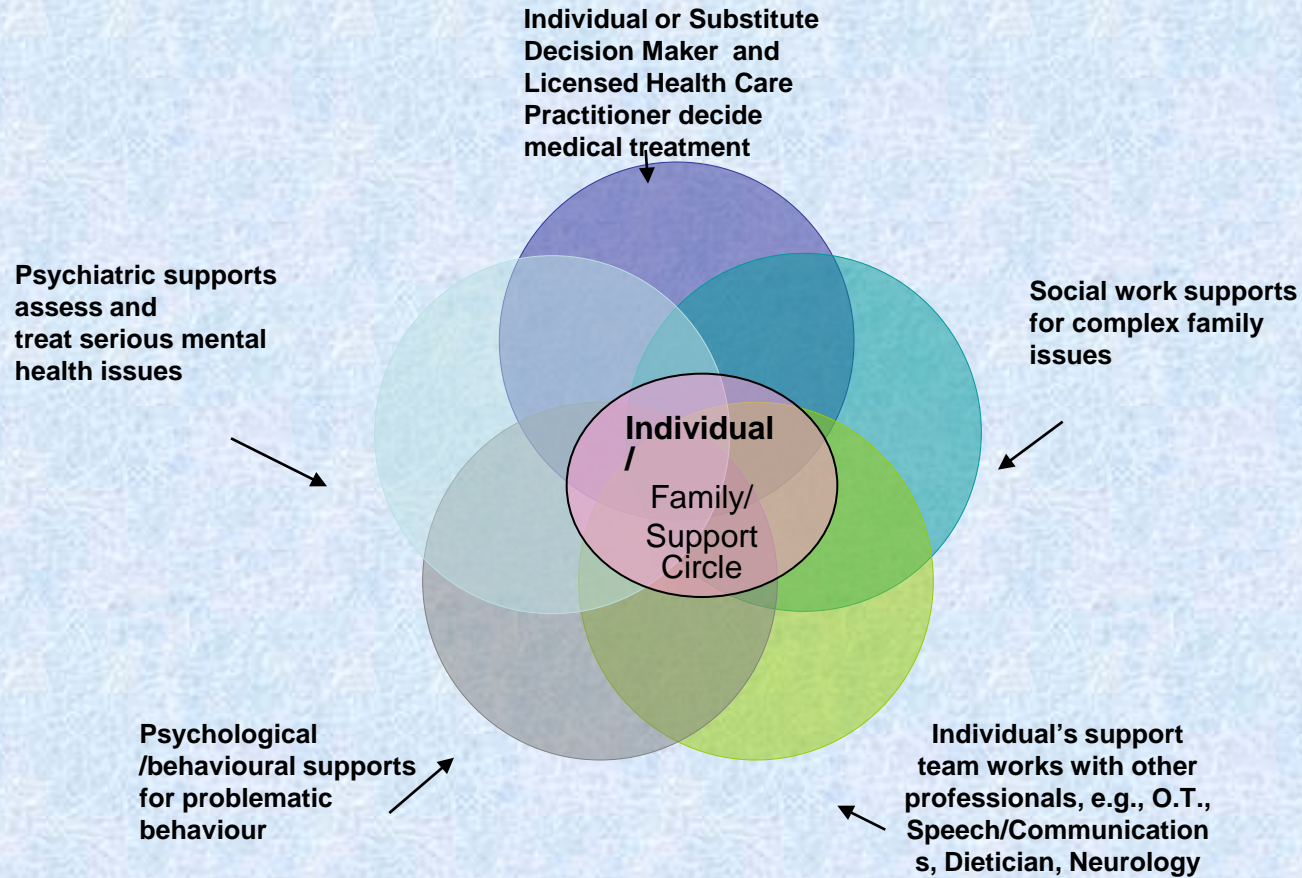
TREATMENT CENTRES

- **Tertiary clinical support necessary when an individual's behaviour or medical condition cannot be managed in the community**
- **Living on a hospital ward can be particularly difficult for many individuals with ASD**
- **Treatment Centres may make admission to tertiary care unnecessary or assist with reintegration**
- **Need effective cooperation/protocols with local hospitals/institutions to facilitate this reintegration**

TREATMENT CENTRES

- **Key Assumption: individuals will move on to more permanent homes in the community at the end of treatment**
 - **Must foster expectation of success**
 - **Key success elements:**
 - **Biopsychosocial (Griffith & Gardner, 2002) model**
 - **Eden (Gerhardt and Holmes, 1994) approach**
 - **staff commitment and hard work**
 - **ensuring effective means of communication**
- (Beukelman & Mirenda, 2005; Wetherby & Prizant, 2000).

KPAS BIOPSYCHOSOCIAL MODEL



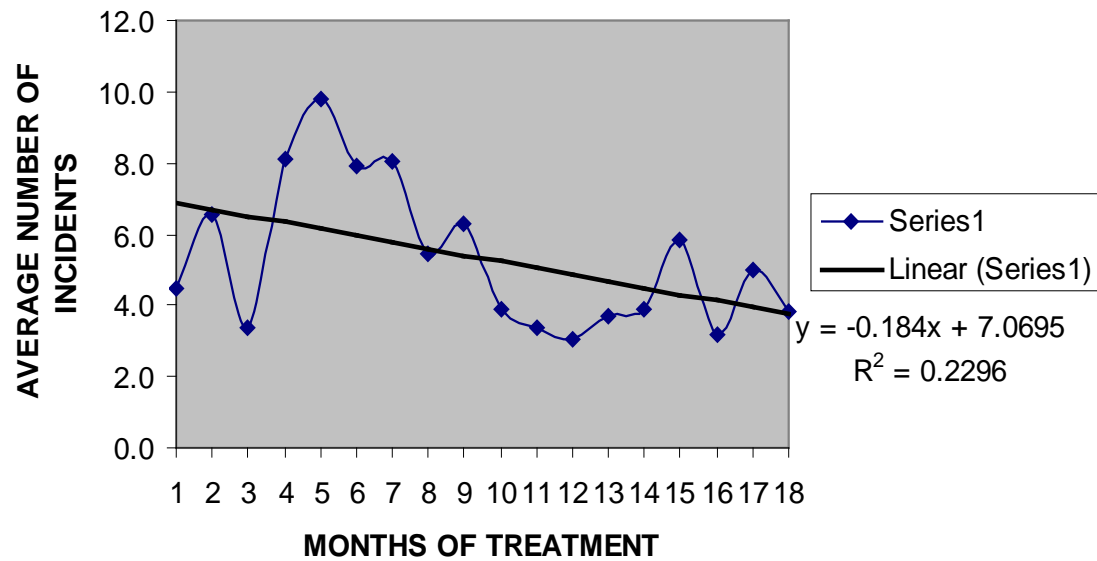
TREATMENT CENTRES (Cont'd)

- **Currently have 20 formally admitted individuals from a variety of community and institutionalized settings**
- **Three previous individuals have graduated to various community living options**

TREATMENT CENTRE (CONT'D)

- **3 “graduates” plus 18 individuals in “treatment for 12 or more months**
- **Progress tracked by reductions of incidents of:**
 - aggression**
 - self-abuse**
 - property damage,**
 - restraint,**
 - sexually inappropriate behaviour**
 - emotional upset**
- **11 individuals in treatment 18 months or more plus 7 in treatment for at least 12 full months.**
- **Anyone in treatment for less time not included in these analysis**

ALL INCIDENTS FOR ALL INDIVIDUALS



TREATMENT CENTRE (CONT'D)

- Total incidents for first six whole months in the treatment compared with the total incidents for the last six months using the paired t-test procedure of the NCSS analysis system (Hintze, 1999)
- The first period averaged 43.8 incidents per person; the second averaged 24.9 (N = 18)
- T-value of 1.903 (df = 17), significant at $p < .05$ with a one-tailed test

TREATMENT CENTRES SUMMARY

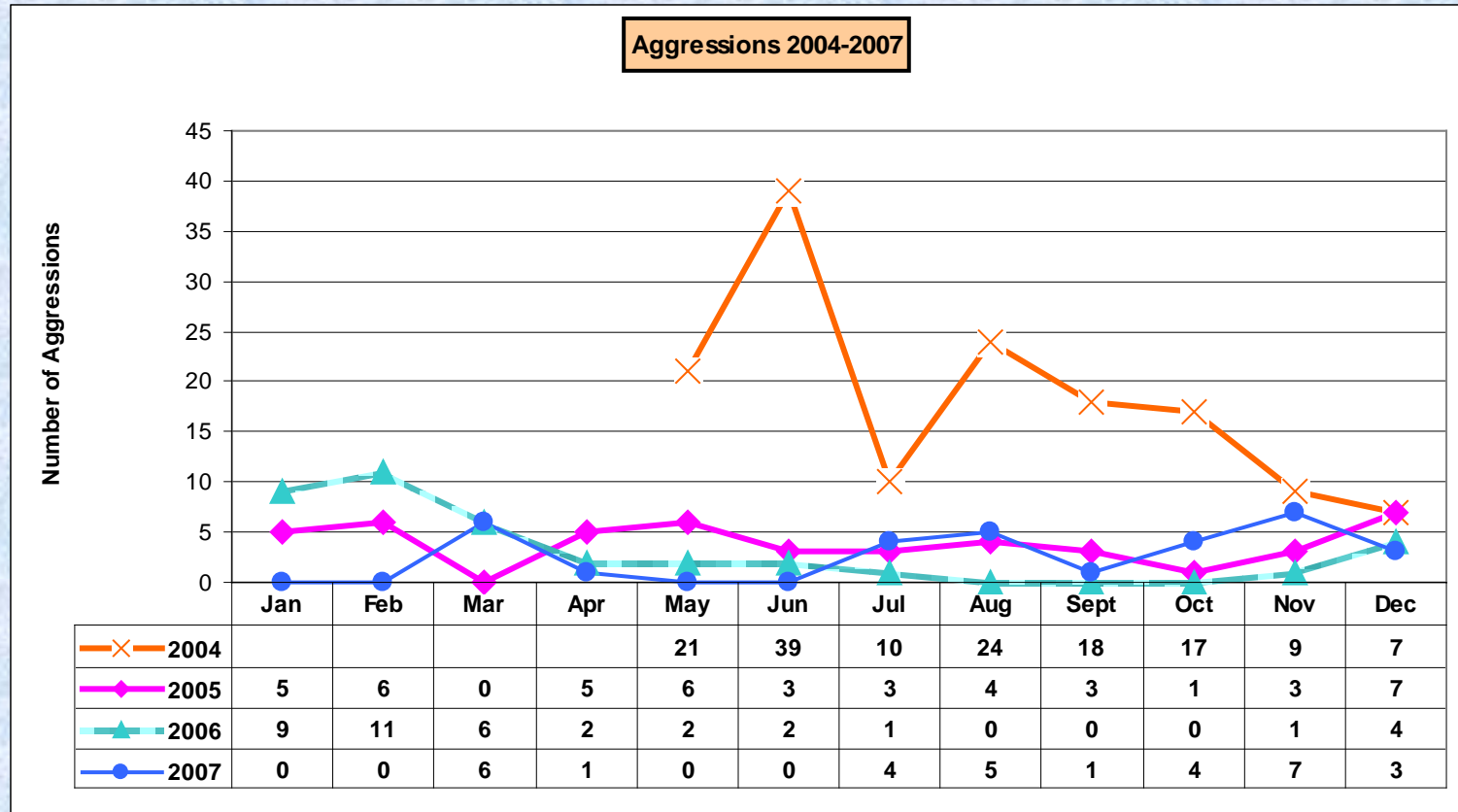
- **Graduation to community living does not mean “cured”**
- **Appropriate follow-up necessary or regression can occur**
- **Negative reputations may hinder acceptance by community agencies**
- **Must help other agencies develop capacity and confidence**
- **Must offer staff training (at all levels), mentoring, and continued professional support to accepting agencies**
- **Reasonable to expect success; not reasonable to expect this to come quickly**
- **Success begets success**

CASE STUDY – K.S.

First Admission – May 2004

- **Attractive young lady with autism with post-traumatic stress and possible psychotic episodes**
- **Spent two years in a psychiatric ward with pessimistic prognosis prior to admission**
- **Verbally and physically aggressive and addicted to restraint.**

CASE STUDY – K.S.



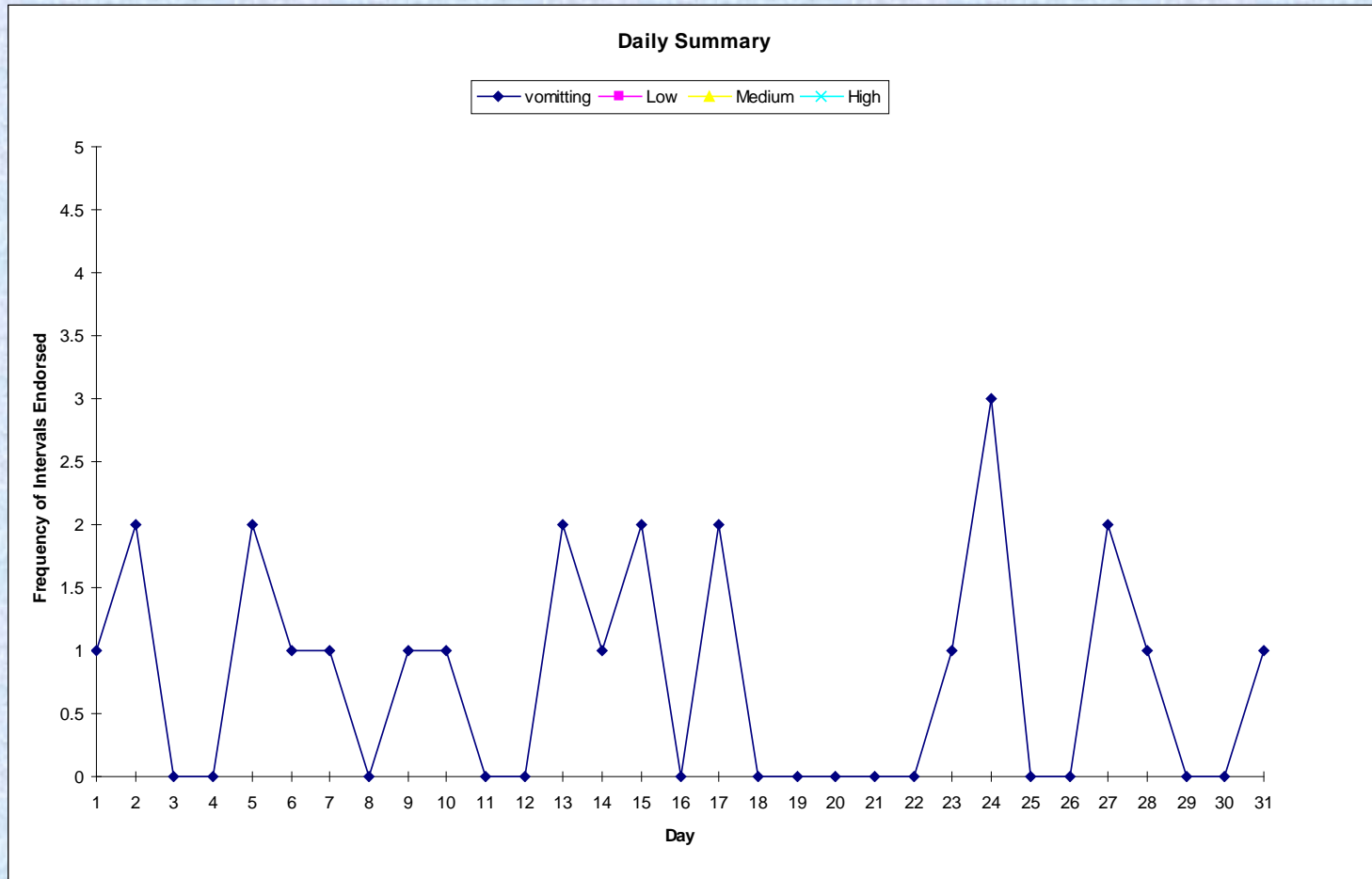
K.S. (Cont'd)

- **Extensive pre-admission assessment and familiarization in psychiatric hospital**
- **Developed a comprehensive plan with protocols re. roles/responsibility of**
 - **KPAS,**
 - **family, and**
 - **continued support from psychiatric hospital**
- **Effective biopsychosocial support team**
- **Environment allowed staff to be in verbal contact but physically separated to**
 - **extinguish restrained motivated behaviour, and**
 - **reinforce other behaviour**
- **Staff especially selected and trained**

CASE STUDY – S.M.

- **Autism and dual diagnosis**
- **Lived in a large institution for most of his life**
- **Arrived early April 2007 with very negative reputation**
- **History of aggression requiring 5 point restraints**
- **History of needing a helmet to prevent biting others**
- **Severe emesis assumed to be attention based**

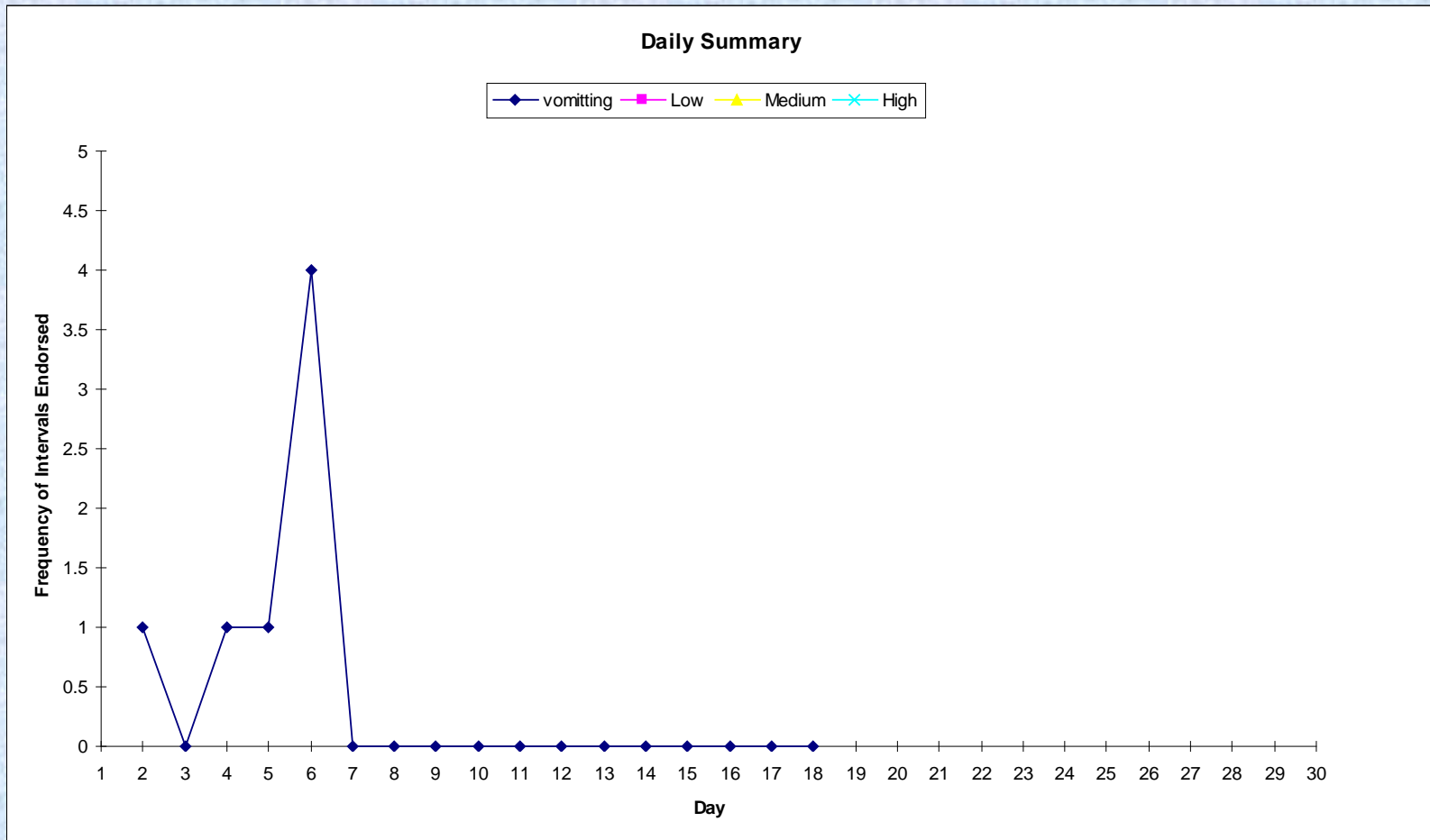
S.M. (Cont'd)



S.M. (Cont'd)

- **Institution medical reports indicated previous alimentary tract problems assessed and addressed**
- **Extinction and D.R.O. had no positive effect on the emesis**
- **Dietician recommended referral to a gastro-intestinal specialist**
- **Subsequent tests found ulcers throughout his upper alimentary tract**
- **Medical treatment almost immediately effective**

S.M. (Cont'd)



S.M. (Cont'd)

- **Helmet faded out prior admission**
- **Physical restraints rare**
- **PRNs rare**
- **Emesis behaviour eliminated**
- **Community inclusion for grocery and clothes shopping**
- **Swims and participates socially with peers**
- **Eats meals regularly with peers**

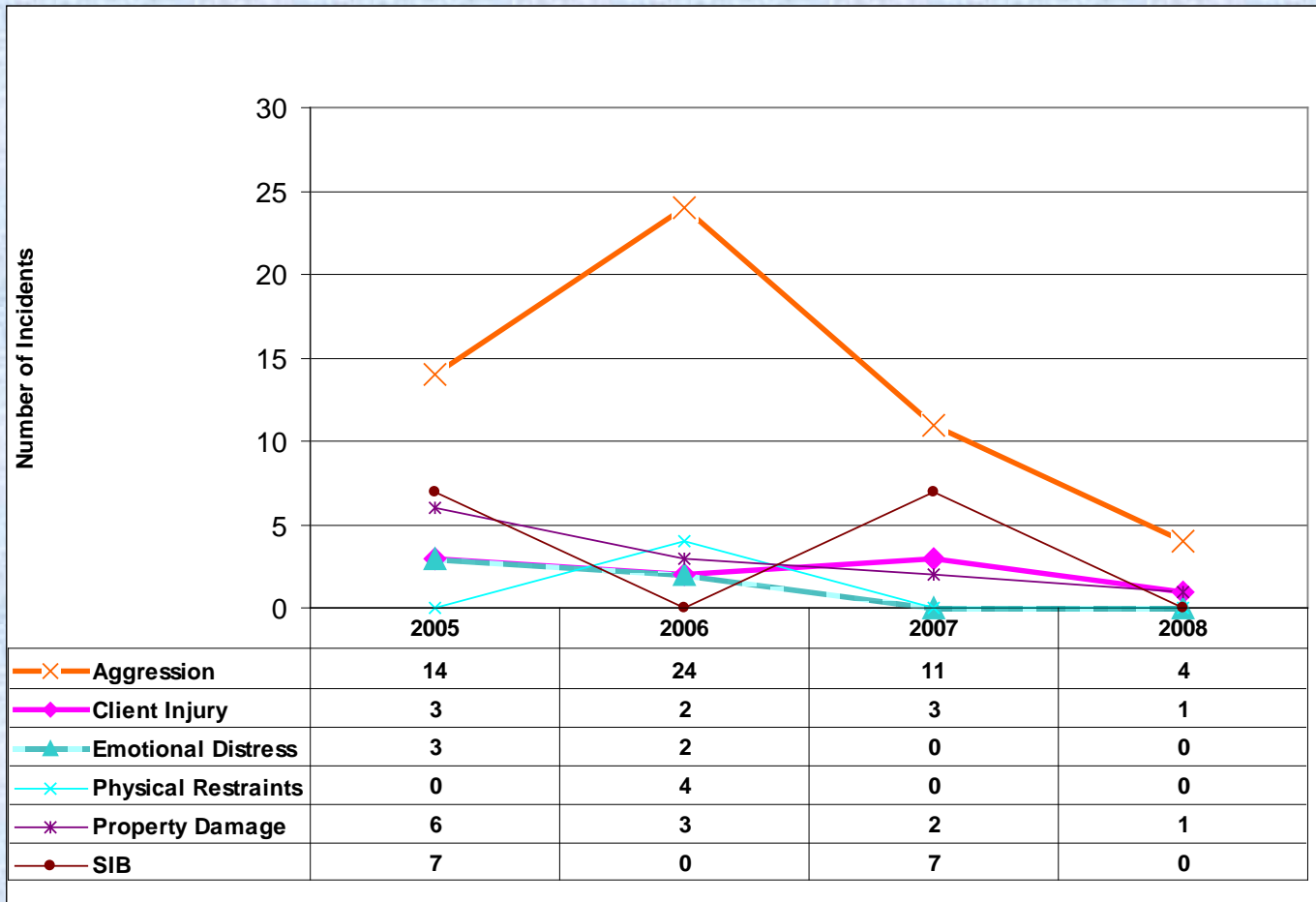
CASE STUDY – H.D.

- Arrived at treatment centre Aug 2006
- Difficult to support for many years due to:
 - verbal and physical aggression; and,
 - urinating and defecating in inappropriate places
- Medication on arrival:
 - Clonazepam - .5mg BID
 - Olanzapine – 17.5 mg QHS
 - Cogentin- 2mg QAM
 - Epival – 500mg QAM
 - Epival -750mg QHS

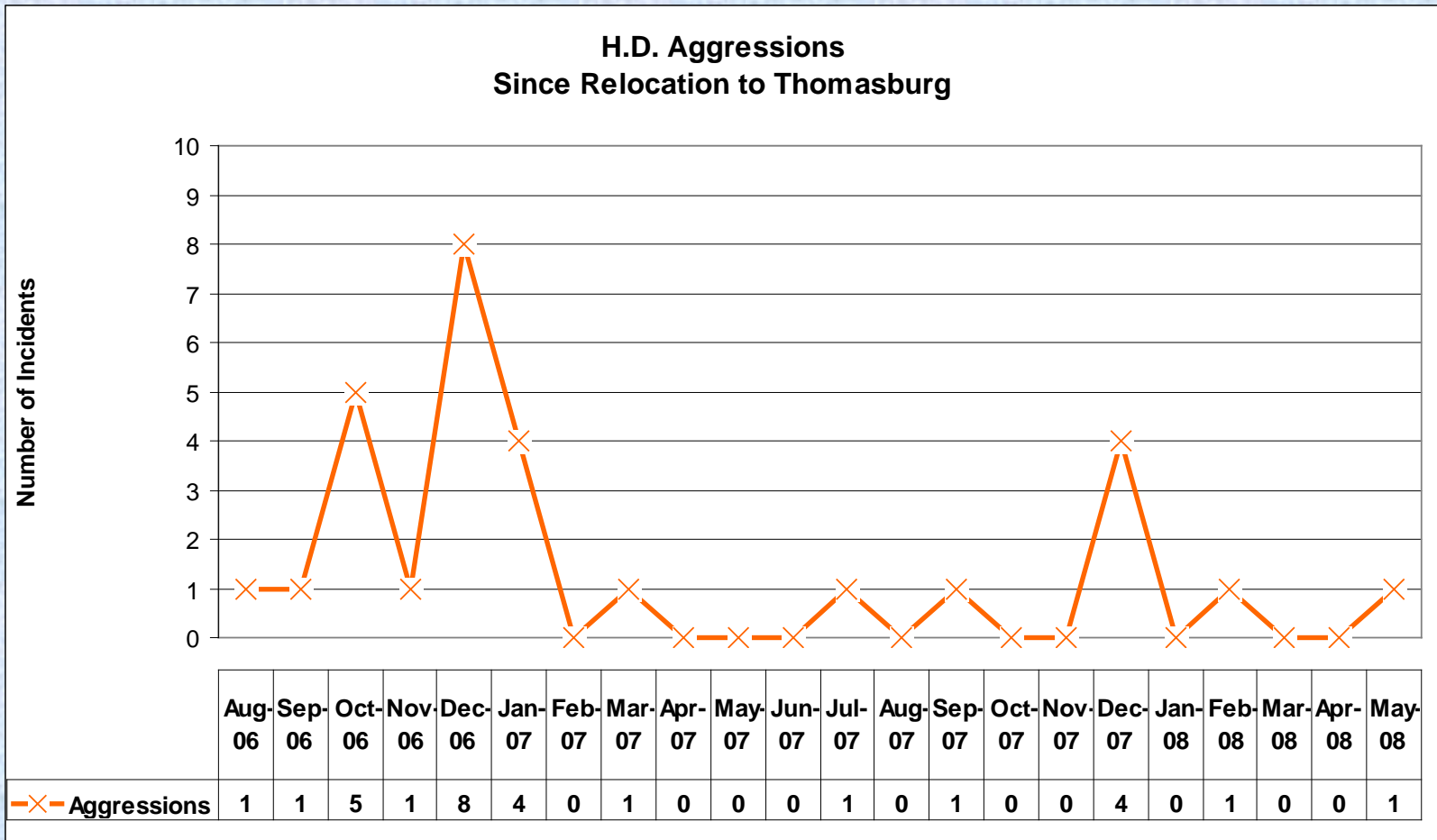
H.D. (Cont'd)

- **Functional analysis indicated behaviour was attention seeking**
- **Extinction program with DRO begun**
- **Olanzapine and Cogentin tapered as behaviour improved**

H.D. (Cont'd)



H.D. (Cont'd)



H.D. (Cont'd)

- **Currently lives relatively harmoniously with 3 others**
- **Playful nature and sense of humour has made him a staff favorite**
- **Current medication - Epival 500mg BID**
- **Ready to be discharged**

CASE STUDY – S. R.

- **Admitted July 2005**
- **Problematic behaviour included:**
 - **Shouting angrily**
 - **Moaning, Growling, Screaming**
 - **Aggression - pushing, pinching, scratching pulling hair**
 - **S.I.B.s - slapping head and ears, hitting head with fist and pulling his hair**

S.R. (Cont'd)

Medication on admission:

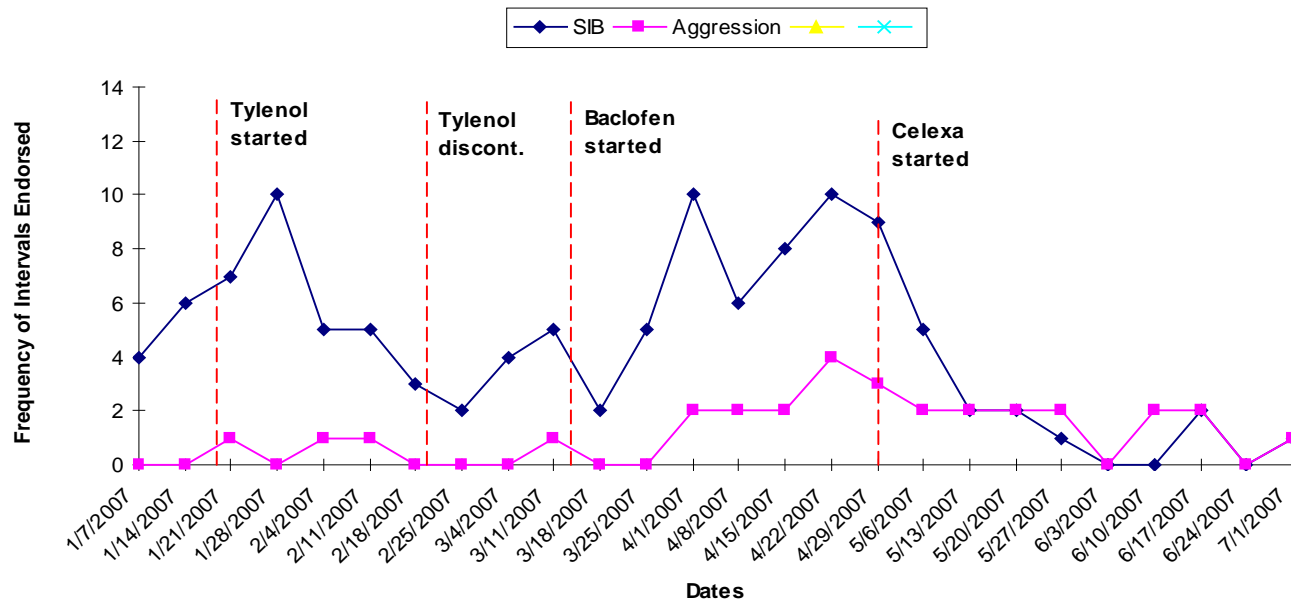
1. **Propranolol-60mg QID**
2. **Valporic Acid-259mg QUD**
3. **Risperidone-1mg TID**
4. **Haloperidol-1mg BID**
5. **Mirtazapine-30mg HS**
6. **Prn's: Lorazepam-1mg, Haloperidol-1mg, Nozinan-50mg**

S.R. (Cont'd)

- **Consulting Psychiatrist began to reduce meds with no change in SIB, but an increase in mobility/balance**
- **Behavioural issues often began in the bathroom but extensive bowel investigations led to no clear diagnosis**
- **Hypothesis that challenging behaviour resulted from pain led to a trial of Tylenol with a seemingly positive result.**

S.R. (Cont'd)

Weekly Summary

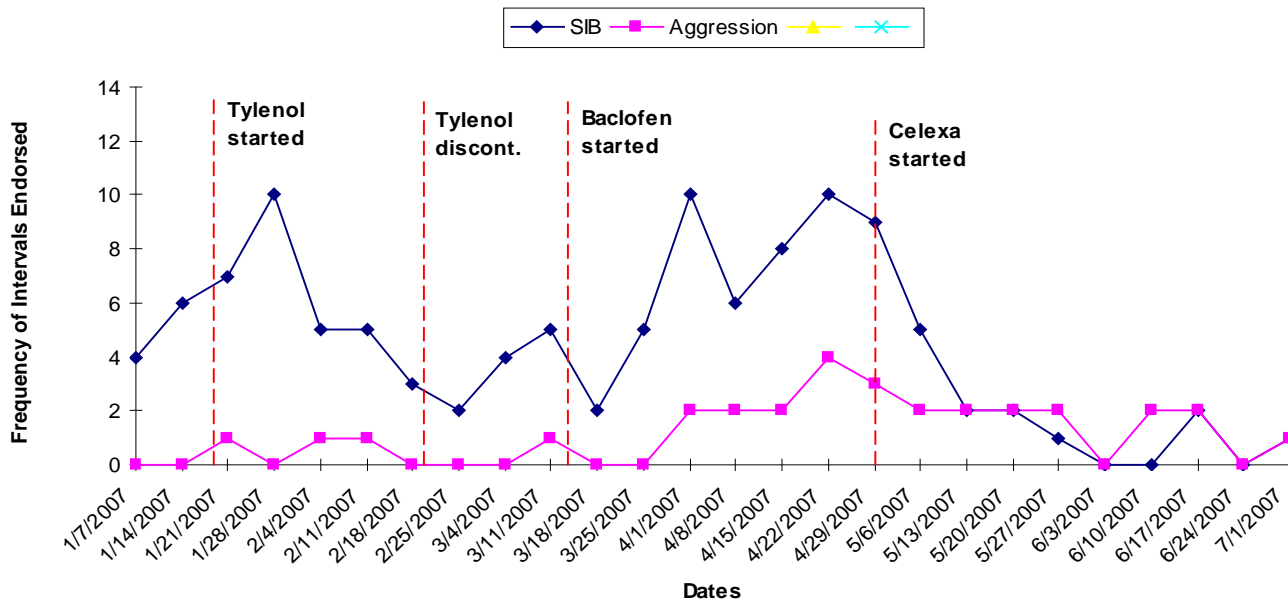


S.R. (Cont'd)

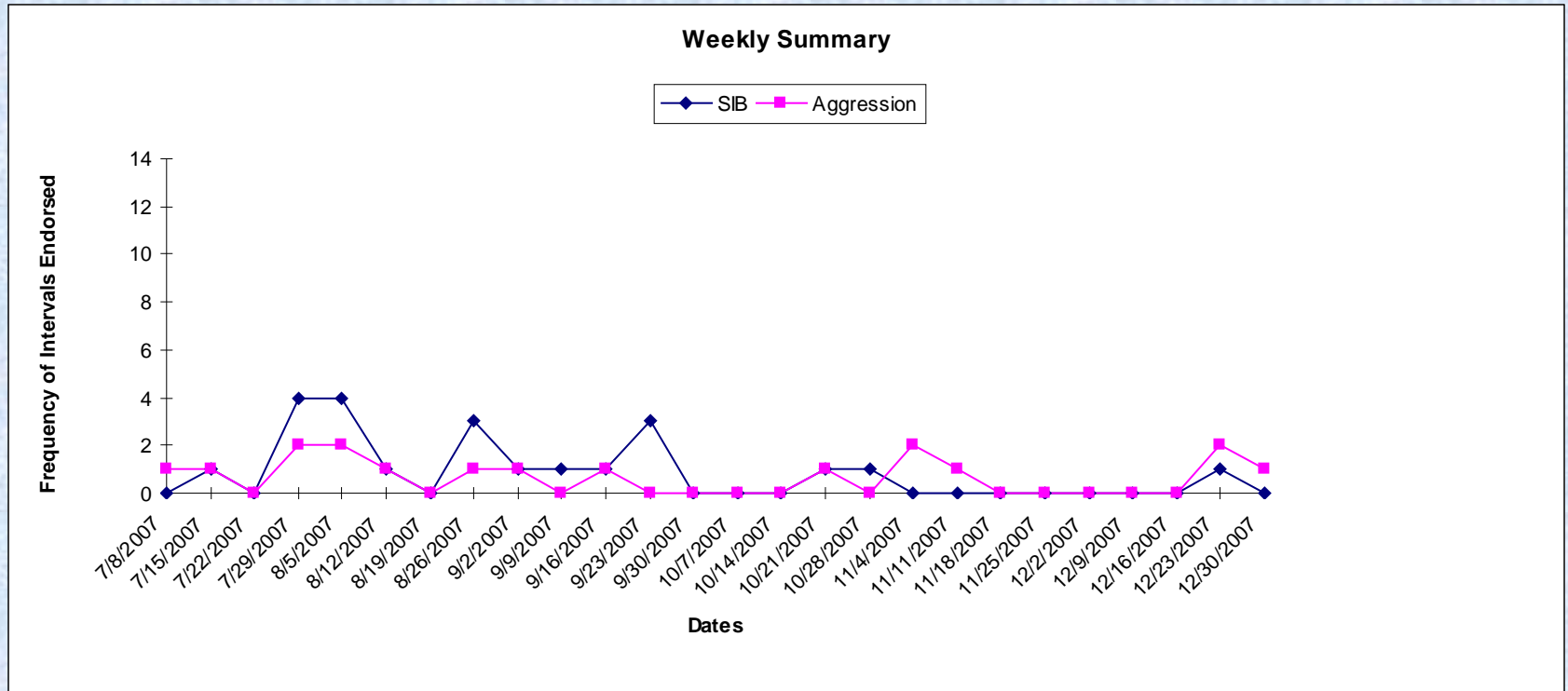
- **Tylenol trial stopped on basis of “anecdotal” feedback – illustrates need to rely on data**
- **After initial positive results of behavioural interventions, S.R. would revert to S.I.B.s and chanting**
- **After an unsuccessful trial with Baclofen consulting Psychologists suggested treatment for O.C.D.**
- **attending Psychiatrist prescribed Citalopram at 40mg**

S.R. (Cont'd)

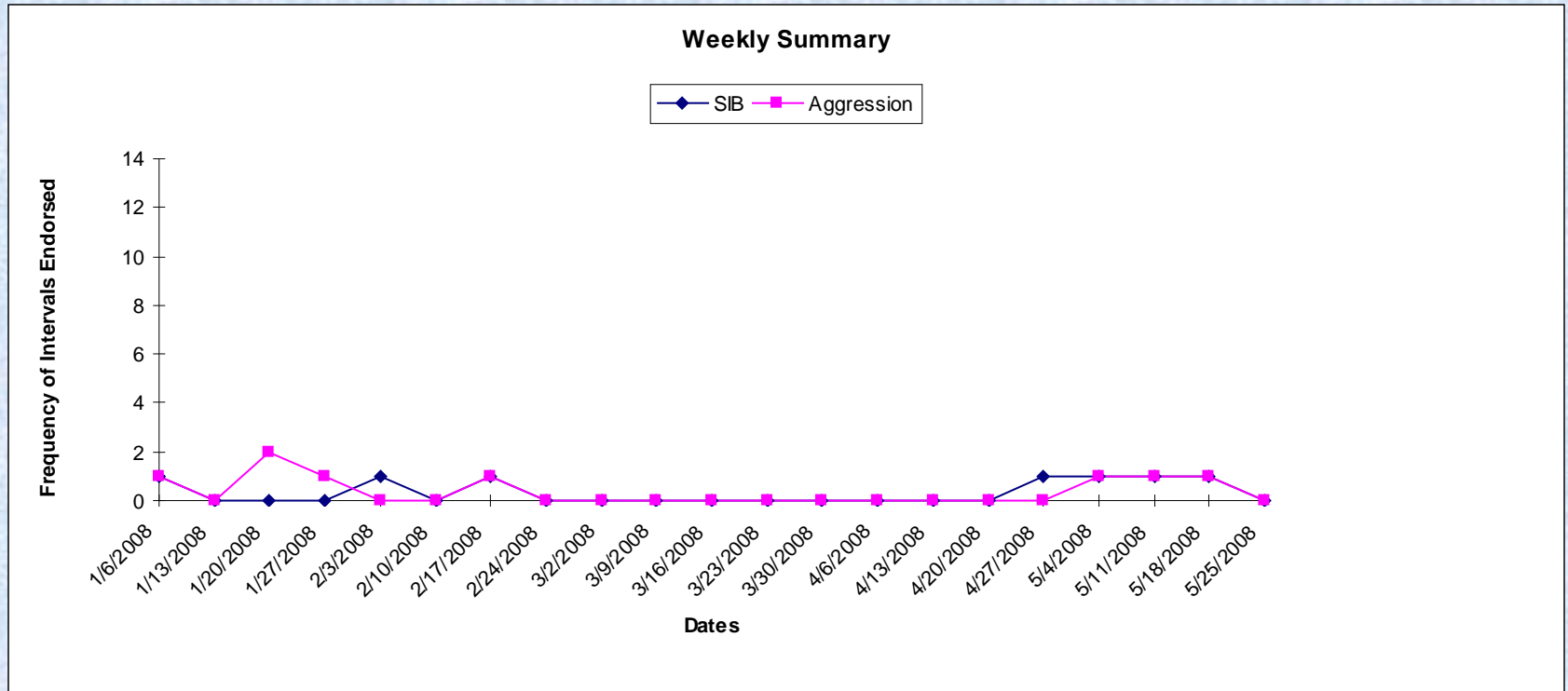
Weekly Summary



S.R. (Cont'd)



S.R. (Cont'd)



S.R. Summary

- **Overall a success story**
- **Illustrates need to base decisions on carefully gathered data**
- **Current medication:**
 - **Celexa-20mg BID**
 - **Risperidone-1mg TID**
 - **Propranolol-120mg BID**
 - **Trazodone-400mg HS**
 - **PRN: Lorazepam-1mg, Acetaminophen 500mg, Melatonin-3mg**
- **Outstanding question:**
 - Can medications be further reduced?**

Experience has taught us the need for:

- **Prevention and early intervention**
- **Extensive prior assessment and in situ orientation**
- **Tailoring environments to needs of the individual**
- **Consistent, effective application of biopsychosocial model**
- **Consistently applied individualized plans that can evolve**

Experience has taught us the need for:

- **Cross-sector collaboration**
- **Family understanding and support**
- **Confident staff trained to support individual's needs**
- **Up-front investment of resources that reduce with progress**

Experience has taught us the need for:

- **Being conservative with risk**
- **Encouraging/supporting research**
- **Systematically gathering data to track the effects of interventions**
- **Sharing lessons learned**
- **Helping each individual develop positive features of their lives**

Limitations of this study:

- **The lack of a systematic, double blind treatment design with appropriate control groups, of course, means that this type of study is not able to determine definitively what approaches are most effective for which individuals**
- **Some individuals had been in treatment for shorter lengths of time than others at the point of the pre-post comparisons – this, along with some other considerations, undoubtedly led to a very conservative indication of the overall treatment effect**

IMPLICATIONS FOR FURTHER RESEARCH

- **Need to study the existence of (and if so reasons for) the “honey-moon” phenomenon**
- **Need to conduct research on which aspects of treatment are most effective, in what combinations**
- **Need to study cost-effectiveness implications of helping individuals move leftwards on the support continuum**

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Front-line staff and individuals involved

THANK-YOU!



KERRY'S PLACE
AUTISM SERVICES

OUTCOME RELATED TO MYSELF

- **People are connected to natural support networks.**
- **People have intimate relationships.**
- **People are safe.**
- **People have the best possible health.**
- **People exercise rights.**
- **People are treated fairly.**
- **People are free from abuse and neglect.**
- **People experience continuity and security.**
- **People decide when to share personal information**

OUTCOMES RELATED TO: MY WORLD

- **People choose where and with whom they live.**
- **People choose where they work.**
- **People use their environments.**
- **People live in integrated environments.**
- **People interact with other members of the community.**
- **People perform different social roles.**
- **People choose services**

OUTCOMES RELATED TO: MY DREAMS

- **People choose personal goals.**
- **People realize personal goals.**
- **People participate in the life of the community.**
- **People have friends.**
- **People are respected**

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